

UNDERSTANDING THE PATIENT'S RECALLED EXPERIENCE OF AN ACUTE EPISODE OF  
GUILLAIN-BARRE' SYNDROME: A QUALITATIVE DESCRIPTIVE STUDY

BY

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and the Graduate Faculty of the University of Kansas  
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Doctor of Philosophy.

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UNDERSTANDING THE PATIENT'S RECALLED EXPERIENCE OF AN ACUTE EPISODE OF  
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## **Abstract**

Guillain-Barre' syndrome (GBS) is a rare disease that affects the peripheral nervous system. It is autoimmune in nature and generally presents with areflexia and paresthesias that can lead to total paralysis. Guillain-Barre' syndrome, with the eradication of polio, is now the leading cause of flaccid paralysis in the United States. This condition produces significant mortality and morbidity challenging the entire healthcare team, but particularly nurses. Guillain-Barre' syndrome is not understood well by nurses. Patients who have experienced a moderate to severe case of Guillain-Barre' syndrome have reported that nursing care was inconsistent. Patients have disclosed that nurses do not have the knowledge related to the special needs of GBS patients. Because of this lack of knowledge, patients experience unnecessary discomfort and/or stress.

Research to better understand the impact of an acute episode of Guillain-Barre' syndrome and the care required during hospitalization is crucial in order to educate caregivers and enhance the patient's care experience. The purpose of this study was to gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome. A qualitative descriptive design was utilized to answer three research questions. Orem's self care deficit theory of nursing was utilized to inform this research study. Data were collected through semi-structured interviews with 14 participants. The sample included 10 females and four males from 19 to 79 years old from eight different states. Inductive content analysis was utilized to analyze the data to establish themes.

Five major themes were identified: physical manifestations of GBS, attitudes and emotions, knowledge and awareness, the value of peer contact, and care concepts. These themes would suggest that healthcare team members, including nurses, do not have an understanding of

the special needs of Guillain-Barre' syndrome patients. Additional work and research is needed to enhance the patient's experience with moderate to severe Guillain-Barre' syndrome.

Implications are evident in the areas of practice, educational preparation of healthcare staff, health policy and future research.

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## Chapter One: Background

### Introduction

Guillain-Barre' syndrome (GBS) is a rare disease that affects the peripheral nervous system. It is autoimmune in nature and generally presents with areflexia and paresthesias that can lead to total paralysis. Moderate to severe cases of Guillain-Barre' syndrome result in significant long-term functional impairments in patients. The functional impairments that accompany Guillain-Barre' syndrome can lead to permanent disability (Frenzen, 2008). Table 1 describes the permanent disability percentages by age category resulting from Guillain-Barre' syndrome (Frenzen, 2008).

Table 1

#### *Permanent Disability by Age*

Age Range	Percent of GBS Patients Permanently Disabled	95% Confidence Interval
18-34	12.1%	10.4% - 13.7%
35-64	22.0%	20.8% - 23.2%
>65	48.8%	47.1% - 50.5%

Note. Adapted from "Economic cost of guillain-barre' syndrome in the United States", by P. Frenzen, 2008, *Neurology*, 71, 21-27.

Guillain-Barre' syndrome, with the eradication of polio, is now the leading cause of flaccid paralysis in the United States (Chalela, 2001; Napgal et al., 1999). During the acute episode, Guillain-Barre' syndrome can lead to total paralysis requiring hospitalization for mechanical ventilatory support. This condition produces significant mortality and morbidity (Hartung et al., 2001) challenging the entire healthcare team, but particularly nurses (Haldeman & Zulkosky, 2005; Murray, 1993; Sulton, 2002; Walsh, 2006). Research is needed to better

understand the impact that an acute episode of Guillain-Barre' syndrome has on patients and the care that is required during hospitalization in order to educate caregivers and enhance the patient's care experience.

### **General Information on Rare Diseases**

The National Institutes of Health (2014) defines a rare disease, also known as an orphan disease, as a disease that impacts less than 200,000 Americans concurrently. Rare disease is a term that represents a heterogeneous set of illnesses that can impact any of the body's systems (Schieppati, Henter, Daina, & Aperia, 2008). When considered cumulatively, rare diseases in the United States are not so rare (Wastfelt, Fadeel, & Henter, 2006). The Office of Rare Disease Research (ORDR), part of the National Institutes of Health's (NIH) National Center for Advancing Translational Sciences (NCATS), reports that there are approximately 6800 rare diseases in the United States (National Institutes of Health, 2014). Rare diseases include such commonly known conditions as Crohn's Disease, Cystic Fibrosis, Duchenne Muscular Dystrophy, Huntington's Disease, Tourette's syndrome and Guillain-Barre' syndrome, just to name a few.

Considering each rare disease individually, one might think that the reach of these illnesses is limited; however, when combining all of the known rare diseases together, more than 30 million Americans are directly impacted and living with a diagnosed rare disease (National Institutes of Health, 2014). This means that nearly one in ten people, almost ten percent of the U.S. population, have a rare disease (National Organization for Rare Disorders, 2014). When considering the population of Europe, an additional 30 million individuals are affected (Wastfelt et al., 2006). With these figures, rare diseases are not so rare and are becoming less rare. Wastfelt et al. (2006) reported that nearly 250 new rare diseases are identified annually. The

increase in rare disease identification is in part due to advances in medical and diagnostic abilities and sophistication in the understanding of pathophysiological processes leading to diseases being placed into more narrowly defined categories (Wastfelt et al., 2006). The identification of rare diseases is anticipated to continue to increase because of these advances.

Rare diseases, and the impact that these illnesses have on patients, families, and caregivers is an important topic to better understand. Diseases that are classified as rare can be life-threatening and cause long-term residual issues (Wastfelt et al., 2006). Patients, and family members, can experience a significant impact on quality of life related to rare diseases and their sequelae (Wastfelt et al., 2006).

### **Rare Disease Awareness and Issues**

Rare diseases, such as Guillain-Barre' syndrome, pose special challenges for patients, their support systems, and providers making these illnesses a critical public health concern (National Institutes of Health, 2014; Schieppati et al., 2008). The focus on rare diseases, and the public's awareness of these illnesses in general, seemed to change in the mid to late 1980's. This change was driven by Congress in 1985 when the National Commission on Orphan Diseases was created and then the subsequent report from this Commission that was produced in 1989 (U.S. Department of Health and Human Services, 1989). This 106-page report detailed the issues that patients, physicians, and others faced when encountering a rare disease.

For patients and families, these issues included: (a) difficulty obtaining information about treatment; (b) a lack of awareness of research advances and availability of clinical trials; (c) lack of information on the sequelae related to their rare disease and the subsequent impact on work and school; (d) the significant financial burdens created by cost of treatment (if a treatment was available for their specific illness) as well as the loss of income; and (e) not being aware of

the availability of resources such as support groups. The lack of information and education that patients reported was also a concern for providers. Physicians caring for patients with rare illnesses revealed that they did not have the educational resources to share with patients and were conservative in diagnosis and treatment secondary to their lack of knowledge on rare diseases. Providers desire more information regarding rare diseases in order to provide better care.

The report highlighted that patient advocacy organizations, and the associated support groups, could contribute to the educational needs of patients and providers. Patient advocacy groups revealed that developing and distributing educational information and providing educational sessions to patients and families had become a primary function. Because of the work of patient advocacy/support groups, the public's awareness regarding rare diseases has increased (Schieppati et al., 2008).

Schieppati et al. (2008) revealed that patients impacted by a rare disease are faced with care that is inadequate, both from a health and social perspective. Because of this, advocacy groups are seeing their purpose as not only including increasing the public's awareness of rare diseases and the subsequent impact on patients and families but also to focus on enhancing care and benefits that patients with a rare disease receive (Schieppati et al., 2008). The Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International supports research efforts related to care enhancements for Guillain-Barre' syndrome patients. Nursing plays a significant role in the provision of care to patients with rare diseases including Guillain-Barre' syndrome. Issues specifically related to the provision of nursing care for patients with a rare disease were not addressed in the Commission's report making this a research priority for future study.



In addition to the National Commission's 1989 report, and the work of disease specific patient advocacy groups (such as the Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International), the National Organization for Rare Disorders (NORD) also is increasing the public's awareness of rare diseases. The National Organization for Rare Disorders sponsors a Rare Disease Day the last day of February of each year. Rare Disease Day was founded in Europe in 2008 by the European Rare Disease Organization (EURORDIS) and initiated in 2009 in the United States by NORD. The purpose of Rare Disease Day is to connect patients, families, caregivers, medical centers, and patient organizations and to gain more attention, including media coverage, for rare diseases and the complications that patients' experience.

### **Guillain-Barre' Syndrome as a Rare Disease**

Guillain-Barre' syndrome impacts more than 5,000 patients annually with an incidence of 1.1 to 1.8 cases per 100,000 individuals (McGrogan, Madle, Seaman, and de Vries, 2009). Guillain-Barre' syndrome is a disorder that is considered to be an acute, typically monophasic, immune-mediated illness (Walgaard et al., 2011). Guillain-Barre' syndrome is accompanied by a variable clinical course (Walgaard et al., 2011). Patients can experience mild symptoms, requiring patients to have assistance with ambulation, to severe symptoms including tetraplegia, requiring patients to be intubated and mechanically ventilated (Nagpal et al., 1999). The severity of illness, and associated sequelae, are related to the variant of Guillain-Barre' syndrome. A detailed discussion of the pathophysiology of Guillain-Barre' syndrome and its variants is covered in Chapter Two. Frenzen (2008) reports that up to 30 percent of patients affected with this illness will have a case severe enough to require mechanical ventilatory support. Patients who reach this level of severity are unable to communicate their needs, verbally or nonverbally,

secondary to paralysis as well as their requirement of intubation and ventilation for survival. Patients are cognitively aware of their surroundings and the happenings within their surroundings during sedation vacations and when the patient has stabilized to a point where they no longer require sedation as previously required secondary to mechanical ventilation. In addition, since GBS patients requiring mechanical ventilator support typically experience tetraparesis, sedating the patient to prevent endotracheal tube dislodgement is not always necessary. Generally, individuals diagnosed with GBS retain cognitive functioning (DeCort, 2011). Despite being cognitively aware of their environment, patients are not able to communicate effectively, or in severe cases, not at all. It is essential to better understand the patients experience during hospitalization with moderate to severe Guillain-Barre' syndrome so care enhancements in nursing and supportive care can be realized.

In addition to the communication challenges, patients who have experienced a moderate to severe case of Guillain-Barre' syndrome have reported that nursing care was inconsistent (DeCort, 2011). Guillain-Barre' syndrome is not well understood by nurses (Murray, 2010). Patients have disclosed that nurses do not have an awareness of the unique care needs of GBS patients which contributes to stress and discomfort that is not necessary for patients to endure (DeCort, 2011) Patients reported that: (a) nursing staff did not understand that paralyzed patients could experience pain (GBS patients experience severe pain), (b) nursing staff did not offer meal assistance to a partially paralyzed patient because they believed the patient should feed themselves, (c) nurses did not understand the proper use of bed side rails, (d) nurses did not provide needed assistance with toileting, and (e) staff did not properly communicate when providing assistance with activities of daily living (Murray, 2010).

A Professor at the University of Auckland (New Zealand) discussed the special needs of GBS patients and their support systems including: (a) the patient's right to information, (b) the right to an effective communication method, (c) the duty of care, (d) provider and staff competence, and (e) the importance of compassion (DeCort, 2011). A call to action was made for GBS patients to share their nursing care experiences (DeCort, 2011). GBS patients are unlike any other patient (DeCort, 2011) and research is needed specifically with this population so that care enhancements can be made.

Although research has examined the long term impact of Guillain-Barre syndrome, including functional impairments, there is little information about the patient experience during a hospitalization with moderate to severe Guillain-Barre' syndrome and the subsequent translation of this information into knowledge for care enhancements. A few patients have described their experience in the way of personal accounts (Bowes, 1984; Henschel, 1978; Rice, 1977; Shearn & Shearn, 1986), and there are also published case studies (Walsh, 2006). Additional information related to the patient experience from personal accounts and case studies is covered in Chapter Two.

Forsberg, Ahlstrom, and Holmqvist (2008) described patients' experiences during the initial phase of Guillain-Barre' syndrome. The study included 35 participants, utilized an interview guide and qualitative content analysis. Subjects in the Forsberg et al. (2008) study included those that presented with mild, moderate, and severe cases of Guillain-Barre' syndrome. The analysis revealed the following four themes: (a) fear and insecurity in a vulnerable situation, (b) distinct hopeful improvement, (c) alarmingly slow recovery, and (d) strange bodily and mental situations. There were 18 subthemes identified (Table 2; Forsberg et al., 2008); however, this is only one study and more research is needed.

Table 2

*Themes and Subthemes Identified in one Guillain-Barre' Syndrome Study*

Theme	Subtheme
Fear and insecurity in a vulnerable situation	Fear of getting worse Frightening to lose body functions Helplessness and shame Life-threatening state of health Feeling isolated because of limited communication Insecurity when being moved to another ward
Distinct, hopeful improvement	Reassured by rapid and steady improvement Distinct turning point was a relief Increasing independency inspired joy and hope
Alarmingly slow recovery	Prolonged time before start of recovery caused doubt Growing awareness of having a serious disease Fear of residual deficits
Strange bodily and mental sensations	The body felt unreal Hurt by pain Annoying numbness Feelings of exhaustion Increased mucous and unpleasant suctioning Scary hallucinations

Note. Adapted from "Falling ill with guillain-barre' syndrome: Patients' experiences during the initial phase," by A. Forsberg, G. Ahlstrom, & L. Holmqvist, 2008, *Scandinavian Journal of Caring Sciences*, 22, 220-226.

Because of the lack of research in this area, and the findings in the Forsberg et al. (2008) study (that also included those patients presenting with a mild case of Guillain-Barre' syndrome), more research is needed to better understand the patient's recalled experience with moderate to severe Guillain-Barre' syndrome with the anticipation of disseminating the findings so that care can be enhanced by providing additional education to caregivers.

## **Increased Awareness of Guillain-Barre' Syndrome**

Guillain-Barre' syndrome became better known to the general United States public in 1976 during an increased incidence of GBS that was thought to be associated with the administration of influenza vaccination against the swine-type influenza A (H1N1) virus (Haber, Sejvar, Mikaeloff, and DeStefano, 2009). More than 45 million individuals from across the United States were vaccinated against H1N1 during the months of October to December 1976 (Haber et al., 2009). During this time period, the number of Guillain-Barre' syndrome cases increased (500 cases reported) as well as mortality related to GBS (25 deaths) (Haber et al., 2009). Haber et al. (2009) revealed that the increase in GBS morbidity and mortality was thought to be associated with the H1N1 immunization program. The increased incidence of GBS between October and December 1976, one additional case of GBS per 100,000 vaccinated individuals, led to the discontinuation of the H1N1 immunization program in January 1977 (Haber et al., 2009). It was reported at that time that additional research was needed regarding the investigation of any link between the immunization and a potential increased risk of GBS (Haber et al., 2009).

The events of 1976 caused an increased level of fear in the general population related to this illness. The Institute of Medicine (IOM) reported that they accepted the notion of a cause and effect relationship between the influenza vaccination program in 1976 and the increase number of adult cases of Guillain-Barre' syndrome (Haber et al.). This connection between immunization and GBS resulted in some individuals electing not to receive influenza vaccination. GBS patients reported having anxiety and fear regarding a relapse if vaccinated (Bowes, 1984). Further research by the Institute of Medicine revealed that there was not enough evidence after the 1976 issue to accept or reject the idea that influenza vaccination caused GBS

(Haber et al., 2009). It is essential to clarify misconceptions about GBS, such as concerns with vaccination, in order to decrease fear and anxiety in patients. Fear and anxiety can impact patient progress and recovery. In addition, it is important to better understand the education provided to patients diagnosed with Guillain-Barre' syndrome so that additional information can be shared and care enhanced. An essential part of nursing care is the provision of information to the patient and family about their illness and to provide adequate psychosocial support (Murray, 1993).

### **Economics of Guillain-Barre' Syndrome**

The financial impact of Guillain-Barre' syndrome is high. Considering direct costs, the cost of medical care, and the indirect costs, such as loss of wages and early death, it was estimated that GBS cost approximately 1.7 billion dollars per year in the United States based on 2004 data (Frenzen, 2008). This economic spend was made up of 0.2 billion in direct costs and 1.5 billion in indirect costs. Direct care costs include costs associated with inpatient hospitalization, rehabilitation and long term care, as well as outpatient care. Table 3 illustrates data regarding the health burden of Guillain-Barre' syndrome as measured by amount of healthcare resources utilized (Frenzen, 2008). This data supports that Guillain-Barre' syndrome is a significant healthcare concern that warrants additional research.

Another study performed by Napgal et al. (1999) specifically looked at treatment costs of the two gold standard treatments (i.e., Plasmapheresis and Intravenous Immunoglobulin) to understand better the financial impacts of these modalities. This study revealed that plasmapheresis was a more economical option (\$6,204 per patient) versus intravenous immunoglobulin (\$10,165 per patient). Hospitalized GBS patients experience a loss of salary,

Table 3

*Annual Health Burden Due to GBS in the United States (based on 2004 data)*

Measure	Inpatient Care Estimate	95% Confidence Interval
Hospitalizations in community hospitals	6,008	5,510 – 6,506
Community hospital patients	5,473	4,951 – 5,995
Discharges to inpatient rehab facilities (IRFs)	1,009	837 – 1,181
Discharges to long term care hospitals (LTCHs)	161	105 – 217
Discharges to nursing homes	720	606 – 834
<u>Outpatient Care</u>		
Physician visits	19,728	0 – 103,506
Physical therapy visits	147,182	0 – 309,820
Occupational therapy visits	7,821	0 – 29,553
<u>Lost Productivity</u>		
Permanently disabled workers	574	512 – 636
Deaths		
GBS was underlying cause of death	247	216 - 278

Note. Adapted from “Economic cost of guillain-barre’ syndrome in the United States,” by P. Frenzen, 2008, *Neurology*, 71, 21-27.

are often underinsured or noninsured, and can have a loss of employment related to length of illness and recovery (Murray, 1993). These factors, including the cost of needed healthcare services, lead to a tremendous source of financial stress for GBS patients (Murray, 1993). It is

important for healthcare providers to understand the financial impact of GBS to the healthcare system overall but also at the patient level. Understanding the patient's concern regarding the financial significance of this illness is important considering the impact of stress on the patient's recovery and progression through the phases of the syndrome.

Nurses play a pivotal role in the delivery of the two primary therapies for GBS, intravenous immunoglobulin and plasmapheresis. Nurses spend a significant amount of time with the patient compared to other healthcare professionals. Intravenous immunoglobulin takes approximately 8.5 nursing hours compared to 17.5 hours for the patients receiving plasmapheresis (Nagpal et al., 1999). This is just one example of the amount of time that nurses spend consecutively with GBS patients. Compared to other healthcare professionals, nurses spend the most time daily with Guillain-Barre' syndrome patients providing nurses the opportunity to make significant impacts on both the psychosocial and physical health of GBS patients (DeCort, 2011). This was an important consideration as this study was concerned with enhancements that could be made to nursing practice based on the patient's recall of events during care.

### **Purpose of Study and Research Questions**

The purpose of this study was to gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome. Guillain-Barre' syndrome is a disabling disorder that has multiple implications for patients. These implications include physical limitations, psychological effects, financial hardship, and stressors on support systems and family. Many of these implications, particularly from a patient's recalled experience about an acute episode, have not been studied fully. This research aimed to better understand what the patient recalls about encounters during an acute episode of moderate to



severe Guillain-Barre' syndrome and what insights could be shared with clinicians to enhance this care.

The study answered the following research questions:

1. What are patients recalled experiences of care and caregiver interactions during an episode of moderate to severe Guillain-Barre' syndrome?
2. What do patients recall about the characteristics and environmental conditions of the clinical area(s) where they received care?
3. How do patients describe their change in knowledge of GBS over time from pre-diagnosis to current time?

### **Theoretical Framework and Theory Assumptions**

Orem's self care deficit theory of nursing was utilized to inform this study. Orem (1995) supported that nurses should have qualifications to develop and deliver nursing care to patients who require nursing assistance. Patients who experience a diagnosis of moderate to severe Guillain-Barre' syndrome will require multiple levels of nursing care because of the physical and psychosocial impacts of this illness that can be devastating (Anderson, 1992).

Orem's self care deficit theory of nursing is comprised of three theories: (a) theory of self care, (b) theory of self care deficit and (c) the theory of nursing systems (Nursing Theories, 2012). Figure 1.1 illustrates the relationships between the key components of Orem's self care deficit theory of nursing. Essentially, the theory of self care is a theory that indicates that the term self care represents the activities that are performed by an individual, or on behalf of an individual, to maintain health, and the theory of self care agency is the ability to perform self care activities (Nursing Theories, 2012). Orem (1985) describes three types of self care requisites including universal self care requisites, developmental self care requisites, and health

deviation self care requisites. Universal self care requisites include the need for: (a) air, (b) water, (c) food, (d) elimination, (e) activity and rest, (f) social interaction, (g) prevention of hazards, and (h) promotion of normalcy (Anderson, 1992).

Figure 1.1. Self Care Deficit Theory

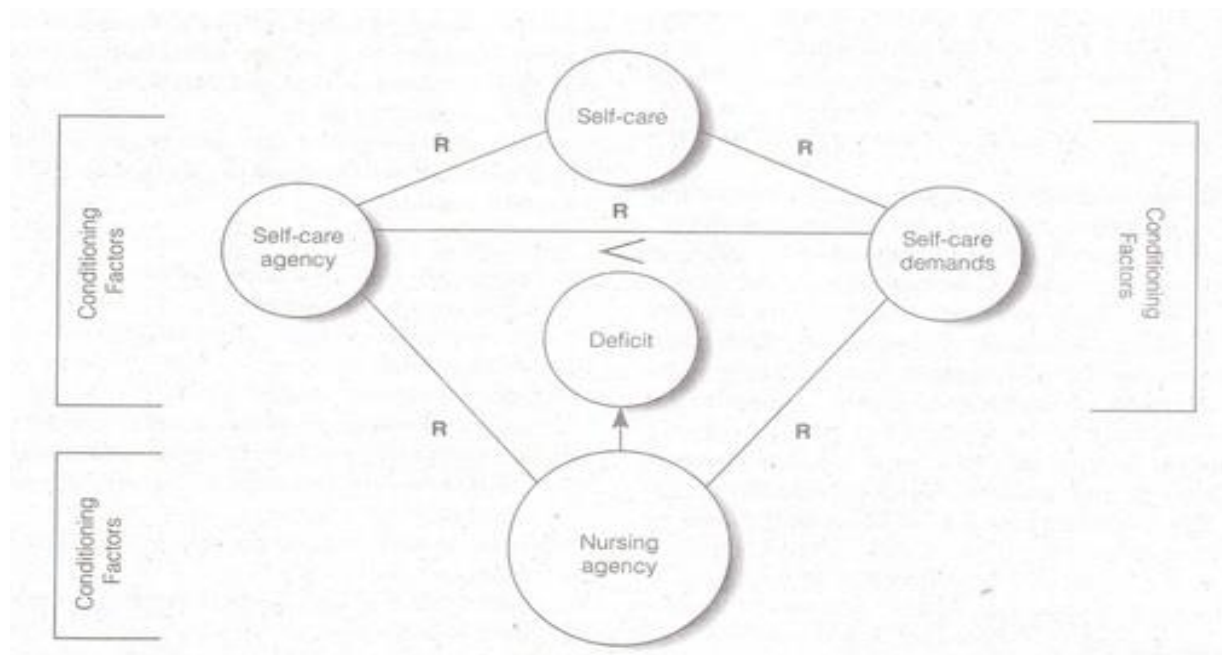


Figure 1.1. Relationship of the major components of Orem's Self Care Deficit Theory. Gonzalo, A. (2011). Theoretical Foundations of Nursing: Dorothea Orem. Retrieved from <http://nursingtheories.weebly.com/dorothea-e-orem.html>.

Because of the significance of paralysis in moderate to severe Guillain-Barre' syndrome patients, universal self care requisites are not able to be met by the patient. If an individual is not able to perform self care, the individual will experience a self care deficit. Self care deficits are identified by nurses by conducting a comprehensive assessment (Nursing Theories, 2012). Once self care deficits are identified, the nurse elects what nursing system will be required to address the patient's needs. Nursing systems include: wholly compensatory, partly compensatory, and/or supportive and educative system (Nursing Theories, 2012). Patients who are diagnosed

with Guillain-Barre' syndrome will experience self care deficits and will rely on nurses to provide care. Based on where the patient is at on the GBS illness trajectory, this care will come in the form of wholly compensatory, partly compensatory, or supportive and educative. Nurses can provide the care that the patient is not able to deliver to themselves, education regarding the illness, as well as psychosocial support (Hudson & Macdonald, 2010). Nurses should be educated as to the best practices when caring for patients with Guillain-Barre' syndrome. Care provided to Guillain-Barre' syndrome patients will be informed by gaining a better understanding of the patients experience with moderate to severe Guillain-Barre' syndrome so that care enhancements can be made. The intent of Orem's work was that it would be utilized in the improvement in nursing care (Cavanagh, 1991).

Patients have reported that nurses misunderstand the needs of Guillain-Barre' syndrome patients and lack the necessary knowledge to provide adequate care and relief of symptoms (DeCort, 2011; Uprichard, Martin & Evans, 1987). Research is needed to better understand from the patient's perspective how self-care requisites can be adequately provided by the healthcare team, particularly nurses.

### **Definition of Terms**

The following terms will be utilized throughout this paper and during the research study. The intent of this section is to provide clarity and consistency regarding definitions for each one of these terms.

1. Guillain-Barre' syndrome – an acute autoimmune polyradiculoneuropathy with a clinical presentation of flaccid paralysis, areflexia, variable sensory disturbance, and elevated cerebrospinal fluid protein without pleocytosis. Guillain-Barre' syndrome is a rare, rapidly progressive disorder that consists of inflammation of the nerves causing muscle weakness (up to

and including paralysis), and is used as an umbrella term for a monophasic, post-infectious, immune-mediated disorder of the peripheral nervous system. Guillain-Barre' syndrome is comprised of several clinical variants including Acute Inflammatory Demyelinating Polyneuropathy (AIDP), Acute Motor Axonal Neuropathy (AMAN), Acute Motor and Sensory Axonal Neuropathy (AMSAN), and Miller Fisher Syndrome (MFS) which are also defined in Chapter Two. Guillain-Barre' syndrome presents at various levels of severity including mild, moderate, and severe cases (Asbury, 2000; Rinaldi, 2013). For this study, participants self-reported a diagnosis of Guillain-Barre' syndrome (including any of the aforementioned clinical variants) as well as moderate to severe level of the illness severity.

2. Mild Guillain-Barre' syndrome - is the point at which an illness with Guillain-Barre' syndrome results in the patient being unable to ambulate without assistance (Burns, 2008)
3. Moderate Guillain-Barre' syndrome – is the point at which an illness with Guillain-Barre' syndrome includes paralysis of at least the lower extremities which results in the patients inability to ambulate (Burns, 2008)
4. Severe Guillain-Barre' syndrome – is the point at which an illness with Guillain-Barre' syndrome results in significant paralysis impacting respiratory musculature yielding the need for mechanical ventilatory support (Burns, 2008)
5. Patient experiences – the sum of all interactions, shaped by an organization's (hospital's) culture, that influence patient perceptions across the continuum of care (The Beryl Institute, 2014)
6. Care – the services rendered by members of the health professions for the benefit of the patient (Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, 2003)

7. Caregiver interactions – the orchestrated touch-points of people, processes, policies, communication, actions, and environment (The Beryl Institute, 2014)
8. Knowledge level – the level of information, understanding or skill that one gets from experience or education; the state of being aware; the fact or condition of having information or being learned; the sum of what is known (Merriam-Webster Dictionary, n.d.)

### **Assumptions of the Study**

This section outlines the assumptions for this study as reflected on and identified by the researcher. Participants were interviewed utilizing different interview techniques (in-person face-to-face interviews or technology assisted which includes electronic face-to-face interviews) based on the geographic distance between the researcher and participant. The assumption is that both interview methods generated equitable data.

This study utilized information obtained during interviews with participants who have a history of moderate to severe Guillain-Barre' syndrome without regard for the time between the acute episode and the interview. Another assumption of this study was that participants were able to recall their experiences during the period of time when they were receiving care for their illness with Guillain-Barre' syndrome. Studies have been performed to determine patient's recall of care events while hospitalized in the intensive care unit (van de Leur et al., 2004; Rotondi et al., 2002).

The assumptions for the current study were based on findings from previous research. Previous research shows that patients do have recall of events that cause discomfort or are considered stressful or bothersome. Van de Leur et al.'s (2004) analyses suggested that there was a positive relationship between discomfort (related to noise, tubes and lines, test and treatments) and recollection of facts [ $p < 0.001$ ]. Rotondi et al.'s (2002) study concurred and

found that individuals who classified a care event or experience as at least moderately annoying had an increased likelihood of recalling that event or experience. Rotondi et al. (2002) further concluded that moderate to extremely bothersome experiences were commonplace and resulted in stress to the patient which made recollection of these events easier. If the patients' experience could be better understood, and symptoms and stressful experiences better managed, the intensive care unit patient could benefit (Rotondi et al., 2002).

For this study, participants self-reported the severity level of their illness with Guillain-Barre' syndrome. The researcher provided information regarding inclusion criteria for the study during consent procedures, indicating that the study was for those participants who had a previous diagnosis of either moderate or severe Guillain-Barre' syndrome. The assumption was that by agreeing to participate in the study, participants were acknowledging that they had previously had a moderate to severe case of Guillain-Barre' syndrome.

The final assumption for this study relates to the recruitment of participants. The researcher assumed that recruiting a number of participants that would allow for informational redundancy was achievable. This assumption was determined based on conversations with leadership team members of the Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International (L. Butler, personal communication, August 26, 2014).

### **Summary**

Guillain-Barre' syndrome is considered a rare disease impacting one to two persons per 100,000. This rare disease is complex due to the number of clinical variants that may present. This acute illness can have devastating consequences up to and including the need for mechanical ventilation in order for the patient to survive. Patients who have moderate to severe Guillain-Barre' syndrome are hospitalized in intensive care units in order to be monitored for

respiratory compromise and the need for mechanical ventilation. In severe cases, patients experience total paralysis leaving them without the ability to communicate verbally or nonverbally. This lack of communication impacts the nurse-patient relationship leaving the patient without the ability to express needs or concerns with care. There is no available research in this area that evaluates the patient's experience during this time. In order to enhance care delivered to patients experiencing this illness during an acute episode of moderate to severe Guillain-Barre' syndrome, research to understand better what the patient recalls about encounters, including caregiver interactions and the context within which the encounter occurred, is warranted. The learnings gained from this study will be shared in order to educate patients and clinicians and otherwise enhance the care provided to patients affected by this illness. By increasing nurses' awareness of Guillain-Barre' syndrome, and the related patient care management strategies for all phases of the illness, nurses will be able to provide a more informed and higher level of care for patients and their families impacted by this unique and challenging illness (Sulton, 2002).

## **Chapter Two: Review of Literature**

The purpose of this Chapter is to provide a review of available literature on Guillain-Barre' syndrome. A search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) was performed utilizing "Guillain-Barre' syndrome" and date limits between 2000 and February 2012. This search resulted in 497 articles. Additional search terms were paired with Guillain-Barre' syndrome to narrow the search and included patient experience (no articles); patient satisfaction (two articles); experience (11 articles); significance (eight articles); fear (one article); death (nine articles); communication (seven articles); anxiety (two articles); and nursing care (16 articles). The abstracts for each of these articles were reviewed. The search term pairings also included the following limits: English language and peer reviewed articles. Studies specific to pediatric patients, and those focused on women who were pregnant at the time of their Guillain-Barre' syndrome diagnosis, were not considered. The results of this review of literature showed that research regarding diagnostic criteria and medical management of Guillain-Barre' syndrome (GBS) were prevalent. Little research exists however that investigates the patient's experience during an acute episode of GBS or the nursing and supportive care necessary to ensure that the patient's experience is as positive as possible. Additional research was needed to better understand the Guillain-Barre' syndrome patient's recalled experience about their acute episode and the nursing and supportive care required to enhance the care experience.

Guillain-Barre' syndrome is a complex illness resulting in significant physical, emotional, social, and financial consequences for patients who experience this illness as well as their families and support systems. The complexity of this illness, the associated sequelae



including tetraparesis and respiratory compromise, as well as Guillain-Barre's classification as a rare disease produces extreme anxiety and fear in patients that are impacted by this disorder.

Previous patients have revealed that the illness, and the associated paralysis, coupled with remaining cognitively intact, causes a feeling of terror on many levels (Anderson, 1992).

Considering this, it is essential for clinical caregivers, and particularly nurses, to have an understanding of this disorder, progression of the illness, available treatments, required supportive care, and expected recovery in order to educate patients and their support systems with the goal of alleviating fear and anxiety and to enhance the patient's care experience.

A review of available studies revealed that little research has been done in the nursing literature to explore the patients recalled experience during an acute episode of Guillain-Barre' syndrome. Additional research was needed to better understand the patient's recalled experience so that practicing clinical nurses and educators could become informed about this illness in order to enhance care provided to Guillain-Barre' syndrome patients. This study describes Guillain-Barre' syndrome patient's recalled experiences so that nurses will better understand the challenges that are part of this disease from the patient's perspective. The information gained from this study will be utilized to inform nursing and supportive care. It is anticipated that health professions staff and their patients will benefit from this knowledge.

### **Guillain-Barre Syndrome**

Since the eradication of polio, Guillain-Barre' syndrome is now the leading cause of neuromuscular paralysis in the United States (Pritchard, 2008). Guillain-Barre syndrome is a disorder of the peripheral nervous system that can result in total paralysis. The effects of moderate to severe Guillain-Barre' syndrome can render a patient essentially lifeless without the ability to move and or communicate. These patients require care in an Intensive Care Unit so

that they can be adequately monitored for disease progression and respiratory compromise. Patients experiencing severe Guillain-Barre' syndrome require mechanical ventilatory support for survival.

### **Incidence of Guillain-Barre' Syndrome**

The incidence of Guillain-Barre' syndrome has been examined by researchers. Three specific research articles on incidence were considered for this paper (Alshekhlee, Hussain, Sultan & Katirji, 2008; Chio et al., 2003; Moore & James, 1981). The studies evaluated incidence of Guillain-Barre' syndrome in the United States, Italy, and Australia. When considering worldwide incidence data, rates have been reported between 0.6 and 4.0 cases per 100,000 population (Chio et al., 2003). In Alshekhlee's et al. (2008) article, the United States National Inpatient Sample Database (NISD) data were utilized. The results concluded, based on data from 2000 to 2004, that the disease incidence was stable over the study period at 1.65 to 1.79 cases per 100,000 population (Alshekhlee et al., 2008). McGrogan et al. (2009) performed a systematic literature review whereby 63 articles were reviewed to establish Guillain-Barre' syndrome's incidence that was reported to be between 1.1 to 1.8 cases per 100,000 population. In McGrogan's et al. (2009) work, there appeared to be an increased number of Guillain-Barre' syndrome cases in patients over the age of 50 where the incidence was reported to be between 1.7 to 3.3 cases per 100,000 population. Commonly the incidence of Guillain-Barre' syndrome in the United States is simply stated to be between 1.0 and 2.0 cases per 100,000. Considering this incidence rate, approximately 5000 individuals will be affected by Guillain-Barre' syndrome in the United States annually (Kogos et al., 2005). In a person's lifetime, the likelihood of becoming ill with Guillain-Barre' syndrome is approximately one in a 1000 (Burns, 2008; Meena, Khadlikar, & Murthy, 2011).

### **Phases of Guillain-Barre' Syndrome**

There are three distinct phases of illness in a patient who has been affected by Guillain-Barre' syndrome. These phases include the: (a) acute phase, (b) plateau phase, and (c) recovery phase. The acute phase begins at the onset of the illness beginning with the first symptoms and continues as the symptoms worsen until clinical deterioration ceases (Anderson, 1992; Atkinson, Carr, Maybee, & Haynes, 2006). Atkinson et al. (2006) reveals that the acute phase can last for up to four weeks and symptoms include pain, muscle weakness, and progressive paralysis that may involve the respiratory system. The plateau phase begins when the symptoms have stabilized and the patient does not exhibit any additional new symptoms (Anderson, 1992; Atkinson et al., 2006). The plateau phase can last for days but often lasts up to several weeks (Atkinson et al., 2006). The final phase is the recovery phase. This phase begins when the patient begins to show improvement in clinical symptoms and lasts until what is deemed recovery for the patient (Atkinson et al., 2006). The rate of recovery in patients is gradual and quite variable (Anderson, 1992; Atkinson et al., 2006). The recovery phase can last from weeks to years (Anderson, 1992; Atkinson et al., 2006). In this phase, the patient will have axonal repair and remyelination of the nerves (Anderson, 1992). Atkinson et al. (2006) indicates that the recovery phase is the phase where the patient begins to show functional improvement, can be weaned from mechanical ventilatory support (MVS), if MVS was required, and is able to utilize extremities that had been impacted by the illness (Atkinson et al., 2006).

Despite patients' clinical improvement during the recovery phase, residual deficits from the impact of Guillain-Barre' syndrome can last for years after the patient regains functional abilities (Atkinson et al., 2006). Researchers have investigated demographic predictors of poor overall recovery. Atkinson et al. (2006) reports that these predictors include patients who are 60

years and older, who experience a rapid progression of the illness, patients that had axonal involvement versus demyelination alone, and those patients who required prolonged mechanical ventilatory support. Many patients will continue to have functional deficits and not return to their pre-illness functional baseline (Frenzen, 2008).

It is essential for nursing team members to have an understanding of the phases of Guillain-Barre' syndrome. Each of the phases of this illness can require different levels of nursing support in order to meet self-care deficit needs of the patient. Based on the phase and the severity of illness, the support provided by nurses could include: wholly compensatory care, partly compensatory care, and/or supportive-educative care (Anderson, 1992; Orem, 1995). The knowledge that nurses gain from this research will inform their practice when caring for patients with this illness and lead to better education of patients impacted by this syndrome as well as enhanced care.

### **Variants of Guillain-Barre' Syndrome**

Researchers now understand that the diagnosis of Guillain-Barre' syndrome actually represents a set of heterogeneous illnesses that have variant immunological pathways (Pritchard, 2008). It is important to understand the variant, or subtype, of Guillain-Barre' syndrome as this informs the clinical team about the symptoms that may be displayed by the patient. In addition, an understanding of the Guillain-Barre' syndrome variant will guide the medical management of the patient as well as yield information regarding the patient's prognosis (Pritchard, 2008). The subtype of Guillain-Barre' syndrome is determined by utilizing findings from the physical exam as well as a determination of how the nervous system is working (Pritchard, 2008). Subtypes are determined based on whether there is axonal impairment or demyelination of the nerve as well as the type of nerve involved, either motor, sensory, or both (Pritchard, 2008). Researchers have

described several variants of Guillain-Barre' syndrome. The four main variants, or subtypes, include: (a) Acute Inflammatory Demyelinating Polyradiculoneuropathy (AIDP), (b) Acute Motor Axonal Neuropathy (AMAN), (c) Acute Motor and Sensory Axonal Neuropathy (AMSAN), and (d) Miller Fisher syndrome (MFS) (McGrogan et al., 2009).

### **Acute Inflammatory Demyelinating Polyradiculoneuropathy**

Acute Inflammatory Demyelinating Polyradiculoneuropathy (AIDP) is what is classically known as Guillain-Barre' syndrome (Asbury, 2000). The terms Guillain-Barre' syndrome and AIDP are often used synonymously. Asbury (2000) provides information regarding Acute Inflammatory Demyelinating Polyradiculoneuropathy. Acute Inflammatory Demyelinating Polyradiculoneuropathy can affect patients throughout the year without regard to seasonality. Acute Inflammatory Demyelinating Polyradiculoneuropathy impacts people in all age groups. Acute Inflammatory Demyelinating Polyradiculoneuropathy is responsible for greater than 90% of the cases of Guillain-Barre' syndrome in North America, Europe, and Australia. Generally the most common clinical presentation with AIDP involves an ascending paralysis with noted sensory nerve involvement. Asbury (2000) reveals that in AIDP symptoms can appear quickly and result in the need for mechanical ventilatory support in as little as 48 hours. Providers treating patients who are experiencing a fever at the onset of the illness should consider other differential diagnoses as patients with GBS are typically not febrile. Changes in cerebrospinal fluid protein levels and electro-diagnostic features that indicate demyelination generally occur after clinical symptoms become apparent.

### **Acute Motor Axonal Neuropathy and Acute Motor and Sensory Axonal Neuropathy**

Axonal forms of Guillain-Barre' syndrome, as opposed to the primarily demyelinating form (AIDP), include (a) Acute Motor Axonal Neuropathy and (b) Acute Motor and Sensory

Axonal Neuropathy. Axonal forms of the syndrome were first highlighted in the literature in 1986 (Feasby et al., 1986). In axonal forms of Guillain-Barre' syndrome, the immune assault targets the axolemma versus the Schwann cells and myelin (Meena et al., 2011). This results in damage to the axon which is what causes the symptoms that the patient experiences. Acute Motor Axonal Neuropathy is typically seen following an infection with *Campylobacter jejuni* and is most common in China (Asbury, 2000). Acute Motor Axonal Neuropathy is more frequently seen in children and young adults and generally occurs as an epidemic during the summer months in rural sections of northern China (Meena et al., 2011). Patients typically present with an abrupt onset of motor weakness with neck and back stiffness that resolves quickly (Meena et al., 2011). Acute Motor and Sensory Axonal Neuropathy more frequently is seen in adults (versus children in AMAN) and is not limited to rural areas in northern China (Meena et al., 2011). Cases of AMSAN have been reported in northern China as well as in Western countries, Japan, and Latin America (Asbury, 2000). Acute Motor and Sensory Axonal Neuropathy differs from AMAN in that sensory nerves are impacted in addition to motor nerves. Acute Motor and Sensory Axonal Neuropathy does not have a seasonal component and is seen throughout the year (Meena et al., 2011). The onset of AMSAN is abrupt and the illness progresses quickly rendering most patients dependent on mechanical ventilatory support within days of the initial symptoms (Meena et al., 2011). Acute Motor and Sensory Axonal Neuropathy is usually a very lengthy illness and has an associated poor prognosis (Meena et al., 2011). Meena et al. (2011) report that only 20 percent of patients diagnosed with AMSAN are able to ambulate one year after diagnosis. Table 4 compares key features of AMAN and AMSAN (Meena et al., 2011).

Table 4

*A Comparison of Key Characteristics of Acute Motor Axonal Neuropathy (AMAN) Versus Acute Motor and Sensory Axonal Neuropathy (AMSAN)*

	AMAN	AMSAN
Seasonality	More common in summer months	Occurs throughout the year without regard to season
Geography	More common in rural areas in Northern China	Can be found in Northern China but not restricted to rural areas; Western world (USA, Canada, Europe, Australia); Japan; Latin America
Typical age of patient	More common in children and young adults	More common in adults
Onset	Abrupt motor weakness	Abrupt onset with rapid progression
Sensory Nerve Conduction Studies	Normal	Abnormal
Needle Electromyography	Denervating potentials seen	Widespread denervation

Note. Adapted from “Treatment guidelines for guillain-barre’ syndrome,” by A. Meena, S. Khadikar, & J. Murthy, 2011, *Annals of Indian Academy of Neurology*, 14(S1), S73-S81.

### **Miller Fisher Syndrome**

Another subtype of Guillain-Barre’ syndrome is known as Miller Fisher syndrome (MFS). This subtype was first described in 1956 by Dr. Charles Miller Fisher (Asbury, 2000; Pritchard, 2008). As in other subtypes of Guillain-Barre’ syndrome, MFS is often preceded by some type of infection (Meena et al., 2011). Patients diagnosed with MFS generally present with a classic clinical triad of symptoms including: (a) ataxia, (b) areflexia, and (c) external ophthalmoplegia (Pritchard, 2008). While the triad of symptoms is the most common

presentation, patients also can have bulbar dysfunction, ptosis, papillary abnormalities, facial weakness, oropharyngeal weakness, internal ophthalmoplegia, and central nervous system involvement (Meena et al., 2011; Pritchard, 2008). Meena et al. (2011) report that unlike the other subtypes of Guillain-Barre' syndrome, MFS typically has a shorter course and is a self-limiting condition with good clinical outcome for the patient with ophthalmoplegia typically resolving in 30 to 60 days, ataxia resolving in 90 to 120 days, and achievement of pre-diagnosis normal activities within 180 days.

Because of the variations that are associated with the Guillain-Barre' syndrome subtypes, it is essential for the clinical team to have an awareness of these subtypes and be educated as to the course of care required for patients and the potential outcomes that may be experienced. This knowledge can then be shared with patients, clinical partners, and the patient's support system in order to keep them informed about how the illness may progress.

### **History of the Illness**

What is now known as Guillain-Barre Syndrome was first described in 1859 by Jean Baptiste Octave Landry de Theizillat (Afifi, 1994; Burns, 2008; Pearce, 1997). Landry first described this illness in ten patients who experienced sensory changes in the extremities and an ascending type of paralysis (Pearce, 1997). In fact, Landry simply called the illness ascending paralysis (Pearce, 1997). Five years after Landry wrote about ascending paralysis, Dumenil related what was being seen in terms of clinical presentation to pathology of the peripheral nerves (Pearce, 1997). No other research was identified in the literature between Landry's work and that of Guillain, Barre', and Strohl. Guillain, Barre' and Strohl's landmark work on the illness was conducted in 1916 when these researchers described the illness in two soldiers (Burns, 2008; Pearce, 1997). The French soldiers presented with areflexia and paralysis



(Galloway, 2006). Haymaker and Kernohan coined the illness Landry-Guillain-Barre's syndrome (Pearce, 1997). Their work presented information on the symptomatology and laboratory findings of the illness in 50 cases that resulted in the patient's death (Burns, 2008). While the patients described by Landry, and those described by Guillain, Barre', and Strohl presented similarly, Guillain did not believe that Landry should be included in the naming of the syndrome because of what he considered to be two distinct differences: (a) poor prognosis in Landry's patients as compared to better prognosis in his patients, and (b) Guillain's collection of cerebrospinal fluid samples (considering confirmation of the diagnosis in Guillain, Barre, and Strohl's work was related to increase levels of protein in the cerebrospinal fluid) (Afifi, 1994; Burns, 2008; Pearce, 1997). Obtaining cerebrospinal fluid samples by spinal tap began in 1891, which was after Landry's description of ascending paralysis and therefore justification to Guillain that Landry's name should not be included in the naming of the illness (Pearce, 1997). Landry's name was not included at all in Guillain, Barre, and Strohl's 1916 article on the syndrome despite the similar presentation of their patients to those described by Landry (Afifi, 1994). Guillain, Barre and Strohl wrote another article in 1919 regarding this syndrome. Subsequent to this article, Strohl's name also was eliminated from the syndrome's name (Afifi, 1994). It is unclear as to the exact rationale for Strohl's name being removed from the syndrome's name; however, there are three schools of thought and include: (a) Strohl's youth only having recently graduated from his medical program, (b) Strohl's birthplace, and (c) Strohl's training as a radiologist instead of a neurologist coupled with his varied research interest (Afifi, 1994). The previous changes, as described regarding the naming of this illness, have lead to what we now know as Guillain-Barre' syndrome. Guillain-Barre' syndrome became better

known as an illness in the general population after an increase in the number of cases in 1976 following influenza vaccination (Afifi, 1994).

### **Preceding Illness and Risk Factors**

Guillain-Barre' syndrome is typically preceded by some type of infection. In fact, studies show that approximately two out of three cases of GBS can be linked to a preceding infection (Dimachkie & Barohn, 2013; McGrogan et al., 2009; Pritchard, 2008). Generally, the antecedent infection will have been recognized between two and four weeks prior to the onset of Guillain-Barre' syndrome (Dimachkie & Barohn, 2013). These antecedent infections can be caused by a virus or bacteria. Infections that precede Guillain-Barre' syndrome can include: (a) *Campylobacter jejuni*, (b) Epstein-Barr virus (EBV), (c) Cytomegalovirus (CMV), and (d) Human Immunodeficiency Virus (HIV), just to name a few (Dimachkie & Barohn, 2013). Commonly, upper respiratory infections precede Guillain-Barre' syndrome (Dimachkie & Barohn, 2013). While the strong association of antecedent infections to the onset of Guillain-Barre' syndrome exist, it is not necessary to screen for these illnesses prior to or once a patient has been diagnosed with Guillain-Barre' syndrome (Pritchard, 2008).

### **Anatomy and Physiology**

Guillain-Barre' syndrome impacts the peripheral nervous system. Considering this, it is important to understand the normal anatomy and physiology of the peripheral nervous system. Knowledge of the components of the peripheral nervous system, as well as the normal anatomy and physiology of the peripheral nervous system, will aid in the understanding of pathophysiologic findings in this syndrome.

## **Normal Peripheral Nervous System Anatomy**

Chawla (2013) provides a review of the nervous system anatomy. There are two divisions of the nervous system: central and peripheral. The peripheral nervous system is the component outside of the brain and spinal cord and includes: (a) cranial nerves, (b) spinal nerves, (c) peripheral nerves, and (d) neuromuscular junctions. There are twelve cranial nerves and thirty-one pairs of spinal nerves. The peripheral nervous system's responsibility is to carry information to and from the central nervous system. Nerve cells, also known as neurons, are made up of three major components: the cell body, dendrites, and the axon. Figure 2.1 presents the normal structure of a typical nerve cell. Dendrites carry electrical information to the cell body whereas the axon carries information away from the cell body. Dendrites of one nerve cell do not touch the axon of another nerve cell. The space between nerve cells is known as the synapse. The transmission of information by way of the nervous system is a complex process. A sensory nerve impulse, known as an action potential, is generated secondary to some sort of stimulus. Dendrites are activated by an electrical stimuli which in turn sends information to the cell body and then to the axon. Chawla (2013) reveals that when the action potential reaches the end of the axon a chemical transmitter, such as acetylcholine (ACh), moves the information across the synapse to the receiving dendrite of the next neuron. Schwann cells located around the axon produce myelin, a lipoprotein, which creates a myelin sheath that insulates the axon (Atkinson et al., 2006; Chawla, 2013). The function of the myelin sheath is to insulate the axon and make the process of nerve conduction more efficient by enhancing speed of transmission as well as allowing for information to long travel distances (Atkinson et al., 2006; Chawla, 2013). The myelin sheath is not continuous (Franssen & Straver, 2013). The spaces between the segments of myelin sheath are known as the nodes of Ranvier (Franssen & Straver, 2013).

Information or signals moving from the dendrites to the axon terminals do not travel the entire length of the axon but rather “skip” to each of the nodes of Ranvier (Franssen & Straver, 2013). Insult to the myelin sheath (or the axon) disrupts the movement of the information or signal being transmitted through the nerve and leads to neuromuscular clinical findings such as those symptoms observed in Guillain-Barre’ syndrome patients (Chawla, 2013). The area of insult, either the myelin sheath, the axon itself, or both, depends on the variant of Guillain-Barre’ syndrome that the patient experiences (Dimachkie & Barohn, 2013).

Figure 2.1. Neuron Key Structures

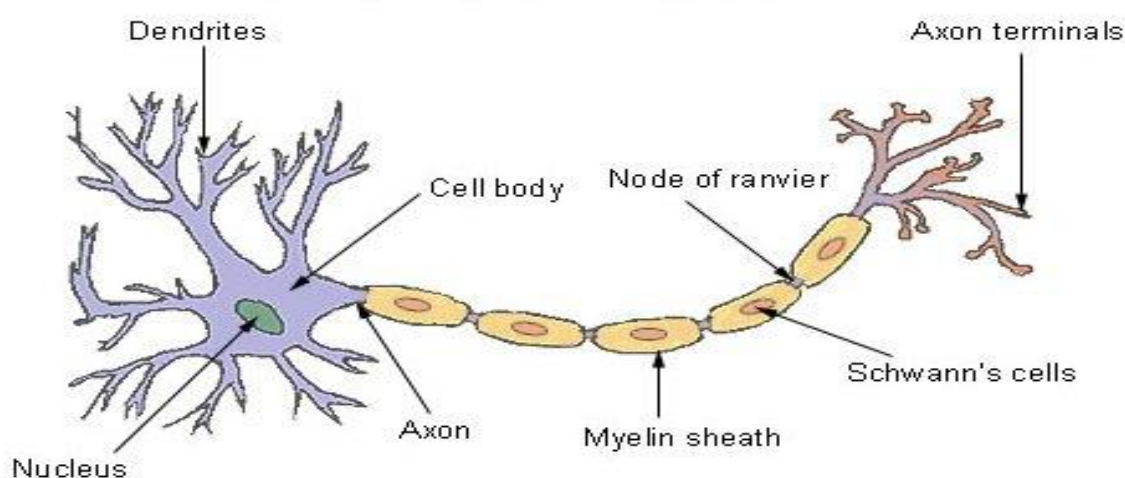


Figure 2.1. Graphic identifying key structures of a typical nerve cell (neuron). Retrieved from <http://training.seer.cancer.gov/brain/tumors/anatomy/neurons.html>.

### Pathophysiologic Findings in Guillain-Barre’ Syndrome

Understanding the pathophysiology of Guillain-Barre’ syndrome is complicated (Rinaldi, 2013). As we see different variants within the overarching illness of Guillain-Barre’ syndrome, we also observe different pathophysiologic presentations. The literature reveals pathophysiologic pathways that occur in Guillain-Barre’ syndrome. These pathophysiologic pathways are related to the variant of Guillain-Barre’ syndrome that the patient is experiencing and includes: (a) the pathophysiologic findings in the acute inflammatory demyelinating

polyneuropathy and Miller Fisher variants, and (b) the pathophysiologic findings in the axonal variants (Asbury, 2000; Atkinson et al., 2006; Burns, 2008; Galloway, 2006; Pritchard, 2008).

Table 5 summarizes key information regarding the pathophysiology of Guillain-Barre' syndrome variants (Asbury, 2000; Galloway, 2006; Leray, 2014 & Pritchard, 2008).

### **Treatment and Management Options**

Currently there is not a known cure for Guillain-Barre' syndrome. In addition, there has not been a treatment identified that has definitely reduced the initial severity of the illness (Parry & Steinberg, 2007). Considering this, clinical management of the syndrome is focused on decreasing the overall severity of the illness, providing supportive care and hastening recovery for patients (National Institute of Neurological Disorders and Stroke, 2011). Atkinson et al. (2006) review four therapies that have been utilized in the medical management of Guillain-Barre' syndrome which include: (a) corticosteroid therapy, (b) cerebrospinal fluid filtration, (c) plasma exchange (or plasmapheresis, PE), and (d) the administration of intravenous immunoglobulin (IVIg). Information regarding treatment options is further summarized in Appendix A. Additional information is needed from the patient's perspective in order to inform nursing and supportive care.

### **Treatment Guidelines**

Based on the studies outlined, and guidance from the American Academy of Neurology Practice Parameters, there are standard recommendations for the treatment of Guillain-Barre' syndrome. Rapid recognition of Guillain-Barre' syndrome is essential when considering treatment options. Patients typically see enhanced benefit of early therapy. Essentially, providers should utilize plasmapheresis or intravenous immunoglobulin as first-line therapy (Atkinson et al., 2006; Dimachkie & Barohn, 2013; Pritchard, 2008). Table 6 illustrates appropriate treatment

Table 5

*Subtypes of Guillain-Barre' Syndrome and Pathophysiologic Presentations*

Subtype	Electrodiagnosis	Pathology	Mechanisms Involved
AIDP	Demyelinating	Initial attack on Schwann cell; widespread myelin damage; macrophage activation; lymphocytic infiltration	T cells directed against myelin proteins
AMAN	Axonal	Attack is at nodes of Ranvier in motor nerves; macrophage activation; few lymphocytes; axonal damage variable	Antibodies directed against GM1, GM1b, GD1a, GalNAc-GD1
AMSAN	Axonal	Similar to AMAN; includes motor and sensory nerves; axonal damage severe; myelin damage occurs but is secondary	Antibodies directed against GM1, GM1b, GD1a
MFS	Demyelinating	Resembles pathophysiology as found in AIDP but mainly affects nerves the oculomotor, trochlear, and abducens nerves	Antibodies directed against GQ1b, GT1a GD3

Note. Svennerholm developed a nomenclature for the identification of gangliosides. The nomenclature includes: G=ganglioside; M=monosialo; D=Disialo; T=Trisialo; GaINAc=N-acetyl galactosamine; The number (1, 2, 3) characterizes the carbohydrate sequence. Adapted from "The gangliosides," by L. Svennerholm, 1964, Journal of Lipid Research, 5, 145 -155.

guidelines utilizing immunotherapy modalities in patients with Guillain-Barre' syndrome based on the patient's ability to ambulate (Dimachkie & Barohn, 2013).

It is important for nurses and patients to understand that the earlier that treatment is initiated, the higher the likelihood of the efficacy of the treatment. Nurses play a key role in educating patients and clarifying information on possible treatments. This education has the potential to engage the patient in decision making as well as reducing the patient's anxiety associated with the disease and the available treatment. When a patient is not aware, or is not prepared, for clinical care that will be initiated, an increase stress level for the patient occurs (Anderson, 1992). Murray (1993) reveals that critical elements of the provision of nursing care in the acute period during hospitalization is around the psychosocial element as well as a focus on increasing the patients' and families knowledge level of illness.

Table 6

*Guillain-Barre' Syndrome Recommended Timing of Treatment Options*

<b>Patients ability to ambulate</b>	<b>Plasma Exchange (Plasmapheresis, PE)</b>	<b>Administration of IVIg (Intravenous Immunoglobulin)</b>
<b>Ambulant</b>	PE is recommended in patients within two weeks of symptom onset (*Level B)	IVIg is not recommended in ambulant patients
<b>Nonambulant</b>	PE is recommended in patients within four weeks of symptom onset (*Level A)	IVIg is recommended in patients within two weeks of symptom onset (*Level A) and up to four weeks (*Level B)

Note. Level A evidence has good scientific support for the recommendation. Level B evidence has fair scientific support for the recommendation.

Adapted from "Guillain-barre' syndrome and variants," by M. Dimachkie & R. Barohn, 2013, *Neurologic Clinics*, 31(2), 491-510.

### **Supportive and Nursing Care**

Because Guillain-Barre' can lead to paralysis of the respiratory musculature, this syndrome is considered a medical emergency (Worsham, 2000). Nurses should feel comfortable

assessing GBS patients frequently to observe for changes due to the progressive nature of this syndrome (George, 1988; Murray, 1993; Worsham, 2000). In order to provide prompt care for patients impacted by the syndrome, nurses should know the progression of the syndrome, basis for diagnosing and treating the illness, and the issues that GBS patients may face while hospitalized (Worsham, 2000). Nurses play an essential role in providing the complex care that is required by GBS patients (Atkinson et al., 2006; Knight, 2011; Sulton, 2002).

Despite the fact that exceptional nursing services, coupled with intensivists level care, are the mainstays of treatment for severely impacted GBS patients, little has been done in the way of research to better understand what improvements could be made in nursing care to enhance the GBS patient's experience (Chalela, 2001). Hughes et al. (2005) provided recommendations for general supportive care for patients. A team of nine individuals met to develop these recommendations. There were no nurses or Guillain-Barre' syndrome patients represented on this committee. In addition, there were no randomized controlled trials to inform this group; and therefore, the recommendations were based on consensus derived from observational studies and expert opinion (Hughes et al., 2005). Table 7 summarizes this and other recommendations related to the nursing and supportive care requirements of patients with Guillain-Barre' syndrome (Atkinson et al., 2006; Chalela, 2001; Haldeman & Zulkosky, 2005; Henderson, Lawn, Fletcher, McClelland, Wijdicks, 2003; Hughes et al., 2005; Hund, Borel, Cornblath, Hanley, McKhann, 1993; Sammonds, 1980; Walsh, 2006; Worsham, 2000).

Due to the scarcity of research in nursing related to GBS, nursing care for patients with this illness have been based primarily on patients who experience periods of immobility and not specifically GBS (Murray, 1993). Additional research is needed to better understand from the



Table 7

*Recommendation for Supportive and Nursing Care*

Issue	Recommendations
Deep Vein Thrombosis (DVT) Prophylaxis (in the nonambulant GBS patient)	Administer Heparin 5000 units subcutaneously every 12 hours or Enoxaparin 40 mg subcutaneously daily  Apply sequential compression devices or anti-embolism stockings  Continue therapies until patient is able to ambulate independently
Cardiac and Hemodynamic Monitoring (in severely affected patients to assess for autonomic dysfunction which can occur in up to 65% of patients)	Monitor blood pressure  Monitor pulse
Respiratory Monitoring and Airway Protection/Timing and Method of Tracheostomy (up to 33% of GBS patients will experience neuromuscular respiratory compromise requiring mechanical ventilatory support; early tracheostomy increases comfort for the patient, enhances airway safety, and may help in weaning)	Monitor respiratory function (assess for the six predictors that suggest the need for mechanical ventilation including: (1) onset of symptoms to admission < 7 days; (2) inability to cough; (3) inability to stand; (4) inability to flex arms or head; (5) increase liver enzymes; (6) vital capacity measurement changes  Provide appropriate tracheostomy care  Utilize ventilator care bundle  Utilize pulmonary function test ratio to estimate ventilator weaning, consider percutaneous tracheostomy placement at 2 weeks post intubation Attempt ventilator weaning once improvement in pulmonary function test  Identify alternate methods of communication secondary to endotracheal tube and/or paralysis (i.e. lip reading, letter and picture boards, blinking, tongue click, minimal pressure activated call light, etc)

Table 7

*Recommendation for Supportive and Nursing Care*

Issue	Recommendations
Pain Management (Pain has been reported by as many as 89% of patients with GBS of which 50% described the pain as severe)	<p>Administer first line therapy: Acetaminophen and nonsteroidal anti-inflammatory drugs</p> <p>Administer oral/parenteral opioids (required by 75% of patients; caution related to side effects)</p> <p>Administer intravenous morphine 1 to 7 mg/hour (required by 30% of patients; use with caution)</p> <p>Consider tricyclic antidepressants or anticonvulsants</p>
Management of Bowel and Bladder dysfunction (Assess for adynamic ileus; constipation; bladder areflexia)	<p>Daily abdominal auscultation to assess bowel function</p> <p>Do not administer promotility agents in patients with dysautonomia</p> <p>Administer stool softener as ordered</p> <p>Bladder catheterization as ordered (avoid use of catheter for urine samples)</p>
Nutrition (GBS is a hypercatabolic state comparable to severe trauma or sepsis)	<p>Administer continuous enteral tube feedings per provider order (Provider should consider high-protein, high-calorie enteral formulas)</p> <p>Can utilize parenteral feeding with TPN if gut not functioning</p> <p>Follow appropriate safety precautions (head of bed elevated, suspend feeding when patient lying supine for care, etc.)</p>

Table 7

*Recommendation for Supportive and Nursing Care*

Issue	Recommendations
Rehabilitation (caution not to over fatigue as this can actually slow recovery; prolonged immobilization leads to reduced blood volume, increase incidence of postural hypotension, peripheral nerve compression, development of pressure sores)	Weigh patient as ordered
	Assess for feeding residuals
	Review nutritional related lab results (i.e. serum albumin, total protein, etc)
	Assess for muscle shortening and development of contractures
	Therapy team should develop an individualized treatment plan
	Follow current guidelines on proper position and turning
Management of Fatigue (severe fatigue persists in as many as 80% of patients)	Consider use of tilt table
	Consider use of alternating pressure mattress overlay or specialty bed
Future Immunizations	Develop exercise program
	Do not administer immunizations during the acute phase of the illness (an up to as long as 1 year post illness)
	If an immunization was given during the 6 weeks prior to GBS illness, consider risk and benefits and need to withhold immunization (discuss with an individual's provider)
	Immunizations, other than as stated above, should not be withheld

patient's perspective the care that was received during their illness with GBS and how this information can be utilized to inform nursing and supportive care.

In addition to the nursing and supportive care recommendations identified in Table 7, intensive care unit nurses must focus on routine intensive care unit patient responsibilities but must also prioritize the psychosocial needs in Guillain-Barre' syndrome patients and their support system (Walsh, 2006). "Providing patients and their families with education, support, and the best nursing care possible will help them cope with the stress and chaos this disorder brings to their lives" (Worsham , 2000, p. 49).

### **Patient and Family Experience**

Patients, and their family members, who encounter GBS experience significant psychosocial issues (Murray, 1993). Table 8 reveals the number and types of publications and studies that were found in the literature regarding the psychosocial and physical needs of Guillain-Barre' syndrome patients.

These studies have identified that patients impacted by Guillain-Barre' syndrome have expressed experiencing fear, anxiety, apprehension, vulnerability, helplessness, guilt, anger, annoyance, frustration, dependence, disappointment, insecurity and isolation (Bowes, 1984; Eisendrath et al., 1983; Forsberg et al., 2008). Patients also revealed feeling depressed and reported having visual hallucinations (Eisendrath et al., 1983). It is important for nurses/nursing researchers to understand these feelings and the factors contributing to them so that nursing care can work to ameliorate these symptoms.

Table 8

*Available Literature from the Patient's Perspective*

Author(s)	Date of Publication	Type of Publication/Research	Number of Participants
Baier, S. & Schomaker, M.	1986	Autobiography	1
Bowes, D.	1984	Autobiography	1
Eisendrath, S., Zimmerman, J., Matthay, M., Layzer, R. & Dunkel, J.	1983	Record Review Interview	8
Forsberg, A., Ahlstrom, G. & Holmqvist, L.	2008	Interviews Qualitative Content Analysis	35
Forsberg, A., de Pedro-Cuesta, J. & Holmqvist, L.	2006	Record Review Interviews Questionnaires x 2 Katz E-ADL Index Review of Computer Registry (utilizing a protocol)	42
Gregory, R.	2003	Autobiography	1
Grove, T., Drain, S., Bruckner, E., Ryder, S., Weagant, L. & Thorndal, C.	1987	Case Study	1

Table 8

*Available Literature from the Patient's Perspective*

Author(s)	Date of Publication	Type of Publication/Research	Number of Participants
Heller, J. & Vogel, S.	1986	Autobiography	1
Henschel, E.	1977 & 1978	Autobiography	1
King, E. & Jacobs, H.	1971	Case Study (pediatric and adult patients)	14
Rice, D.	1977	Autobiography	1
Shearn, M & Shearn, L.	1986	Autobiography	2*
			(*Patient and family member)
Uprichard, E., Martin, A., Evans, S.	1987	Interviews	3
Ventres, W.	2013	Autobiography	1
Weiss, H., Rastan, V., Mullges, W., Wagner, R. & Toyka, K.	2002	Interviews	49

**Available Resources for Patients/Families with Guillain-Barre' Syndrome**

Health professionals need to be aware of resources to support patients and their families during the acute GBS event as well as during the period of recovery. Patients and their families have access to the Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International, an international organization that was founded in 1980 by the Benson family. The organization is an international group of 30,000 members

representing 182 chapters in 33 countries ([www.gbs-cidp.org](http://www.gbs-cidp.org)). Estelle and Robert Benson founded the nonprofit organization in response to Robert's illness with Guillain-Barre' syndrome. The organization was born in the Fall of 1980 with eight people who came together as the Guillain-Barre' Support Group around the Benson's dining room table. The group grew to 25 members in 1981 based on referrals from 32 Philadelphia hospitals. The group registered with the National Health Information Clearing House and a GBS Hotline was established to field calls from all over the United States. The organization grew to 100 members by 1983 and a medical advisory board, chaired by Dr. Asbury, was created.

The mission and vision of the organization is presented on the organization's website ([www.gbs-cidp.org](http://www.gbs-cidp.org)). The mission of the organization is to enhance the quality of life for those individuals around the world, and their support systems, who have been impacted by GBS or an associated illness. The foundation plans on achieving its mission by: (a) "providing a network for all patients, their caregivers and families so that GBS (or CIDP) patients can depend on the Foundation for support, and reliable up-to-date information", (b) "providing public and professional educational programs [on a worldwide basis] designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants", and (c) by "expanding the Foundation's role in sponsoring research and engaging in patient advocacy". The vision of the organization is that individuals who have been diagnosed with Guillain-Barre' syndrome will have "convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services". It is essential for healthcare providers to know about this important resource for patients and their support system so that this information can be shared.

### **Summary**

Guillain-Barre' syndrome is often a catastrophic illness in moderate and severe cases. Patients are often confused, anxious and fearful about the diagnosis and the path that they will encounter. Because the syndrome is classified as rare, many practitioners have not had the opportunity to care for patients with this diagnosis. Future research is needed in the area of nursing and supportive care (Henderson et al., 2003; Hughes et al., 2005) to better understand the GBS patient's experience in order to educate practitioners to enhance and ensure the delivery of high quality patient focused care.



## **Chapter Three: Methodology**

### **Introduction**

Guillain-Barre' syndrome is a disabling disorder that has multiple implications for patients. These implications include physical limitations, psychological effects, financial hardship, and stressors on support systems and family. Many of these implications, particularly from a patient's recalled experience about an acute episode, have not been fully studied. The purpose of this study was to gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome. This chapter outlines the methodology that was utilized in the study. Key areas presented in this chapter include an overview of the research design, a description of the sample and setting, the process for data collection, how trustworthiness and credibility was achieved, the data analysis plan, and ethical considerations including the process by which participants were protected.

### **Research Design**

To achieve the stated purpose, this study utilized a qualitative descriptive research design with inductive content analysis. The rationale for selecting the qualitative descriptive approach is that qualitative research designs, in general, equip researchers with techniques that can explore a participant's view of a human problem (Creswell, 2009). The qualitative descriptive research design specifically aims to provide a rich discussion of an individual's experience keeping the researcher close to the data which is the participant's own words (Neergaard et al., 2009). The qualitative descriptive design was chosen for this study in order to describe the patient's recalled experiences during a moderate to severe case of Guillain-Barre' syndrome. The major focus of this study was to provide a comprehensive account, in the words of the patient, of the recalled experience of care, caregiver interactions, patient knowledge of the illness and the environmental

conditions present during an acute episode of Guillain-Barre' syndrome. This qualitative descriptive research approach allowed for the description of a human problem (care during an acute episode of GBS) and kept the researcher close to the data.

Qualitative descriptive design is the preferred method when a straight account of an experience or occurrence is the goal and this design is commonly used in practice disciplines including nursing (Sandelowski, 2000). This study explored what the patient recalled about experiences during an acute episode of moderate to severe Guillain-Barre' syndrome so that information could be gleaned and shared with educators and clinicians to enhance the care provided to patients affected by this syndrome. A review of the literature as presented in Chapter Two reveals that few empirical studies have addressed the patient's recalled experience during an acute episode of Guillain-Barre'. The qualitative descriptive design was chosen because of the significant gaps that exist in the literature related to this phenomenon. The qualitative research design is ideal for studies that seek to explore the patient experience related to a disease or illness state where little information has been published. Qualitative research, in general, encompasses designs that researchers can use to explore and describe the human experience with health and illness as well as care delivery and care environments (Magilvy & Thomas, 2009). The research questions for this study ask "how" and "what" questions which allows for an emerging design (Creswell, 2009; Onwuegbuzie and Leech's (2006). This allowed the participants experiences to guide further exploration and further questions to emerge. The research questions for this study provided the direction for the research design (Onwuegbuzie & Leech, 2006).

### **Sample and Setting**

Determining sample size in qualitative study requires significant reflection. Researchers utilizing a qualitative study design use their judgment when selecting a sample size (Munhall, 2007; Sandelowski, 1995). The goal in qualitative research is to reach informational redundancy where the researcher is not identifying any new ideas from newly interviewed participants (Sandelowski, 1995). Magilvy and Thomas (2009) reveal that sample size in qualitative descriptive studies can range from three to twenty participants. In light of this range, multiple other qualitative descriptive research studies related to patients' encounters with an illness were reviewed to assess sample size (Anderson & Fagerlund, 2012; Granger, Sandelowski, Tahshjain, Swedberg & Eckman, 2009; Mousing & Lomborg, 2012). Sample sizes in these studies were 13, 12, and 11, respectively. Considering the goal of reaching informational redundancy and a review of other research studies, it was anticipated that ten to twelve individuals would participate in this study. The researcher was mindful throughout the research study of what data were collected and what the data were revealing allowing the researcher to know when enough participants had been interviewed to reach informational redundancy.

Criteria for inclusion in the study were: (a) adult patients 18 years of age and older, (b) individuals with a prior self-identified diagnosis of moderate to severe Guillain-Barre syndrome, (c) individuals who were alert and oriented, (d) individuals able to respond to interview questions, (e) individuals with English as a primary or secondary language, and (f) those who were able to give informed consent.

Exclusion criteria were individuals: (a) less than 18 years of age, (b) that were nonverbal, (c) without the ability to read or speak English, (d) who were currently hospitalized, and (e) with a diagnosis of Chronic Inflammatory Demyelinating Polyneuropathy.

Study subjects were recruited after approval by a Midwestern academic medical center Institutional Review Board (IRB) and were purposively selected using four primary strategies. These strategies included: (a) notification of the Guillain-Barre' Syndrome/ Chronic Inflammatory Demyelinating Polyneuropathy Foundation International's (GBS Foundation) network of members through email to advise them of the study and to ascertain their interest in participating, (b) announcement of the study on the GBS Foundation's website, (c) announcement of the study on the GBS Foundation's Facebook<sup>®</sup> page, and (d) snowballing (or networking) technique. The combination of these four recruitment strategies allowed for maximum variation in participants.

The Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International has an extensive network of members. Typically, these members are persons who have been impacted by Guillain-Barre' syndrome (or Chronic Inflammatory Demyelinating Polyneuropathy but these individuals will not be utilized in this study). Other members of the organization include family members of individuals who have had GBS, professional clinicians and lay caregivers who have provided support to an individual who has experienced GBS, as well as industry vendors who have developed or provided treatment/treatment options to patients who have experienced GBS. Only individuals who had moderate to severe GBS qualified for this study. The GBS Foundation was in support of this research and agreed to assist in marketing the study. Their letter of support is included in Appendix B.

The GBS membership were notified of the study through electronic email (Appendix C). The email letter described the study's purpose and inclusion parameters, was written by the researcher, and was approved by the dissertation committee and the Foundation's Executive

Director (or designee). After all approvals had been obtained, including Institutional Review Board review, the email notification was sent to the GBS Foundation membership from the Executive Director.

The Guillain-Barre' Syndrome Chronic Inflammatory Demyelinating Polyneuropathy Foundation International was instrumental in the recruitment of participants for this study. The Foundation notified potential participants of this research study by email as indicated. Specifically, the GBS Foundation had email addresses of interested parties located within their database. The database was initiated by the Foundation in order to manage email addresses and other pertinent information about its members. Maintaining the database allowed the Foundation to send communication to individuals that may be interested in participating. Their members had already identified that they would be interested in receiving information from the Guillain-Barre' syndrome/Chronic Inflammatory Demyelinating Polyneuropathy organization. The Guillain-Barre' syndrome Foundation holds the membership information in a confidential manner and did not release any membership information from the database to the researcher. The researcher did not have access to the GBS Foundation membership email list. The GBS Foundation identified possible participants based on their physical address in their database. If an interested party lived within a 50 mile radius of the major metropolitan area where the researcher lived, they received an email with the study information. It was the potential participant's responsibility to review the information and reach out via email or phone to the primary researcher. In addition, the Foundation also posted the research announcement on the organization's website as well as on the organization's official Facebook page. This opened up the study to participants regardless of geographic locale.

The researcher had also planned to use snowball sampling (chain or network) technique to accrue the study sample. The snowball technique is achieved by the researcher asking participants to identify other potential participants (Polit & Beck, 2004). This strategy was only utilized at the beginning of the study with the first two participants. The snowballing technique was stopped by the researcher when it became evident based on the number of responses to the study's announcement that this strategy was not going to be needed.

In the case of this study, the researcher asked the first two participants to consider sharing information regarding the study with other known Guillain-Barre' syndrome patients. This request occurred at the end of the interview. Specifically, the researcher provided the participant with a written notification (Appendix D) that requested the individual to share study information with others who they think may be interested in participating in this research. The notification included directions about how potential future participants should contact the researcher. The researcher reviewed the information and was clear that referral of another individual and the subsequent participation of the referred individual was completely voluntary. The researcher used caution to ensure that the participant did not feel pressured to make a referral. This technique has advantages because it connects the researcher with potential participants that the researcher may have not known about or had access to. In addition, this technique can often lead to trust building with a potential participant more quickly since participants are referred by individuals that they know and have a relationship with (Polit & Beck, 2004). Because of the number of interested potential participants, the snowballing strategy was discontinued early in the study.

If additional participants were needed to reach informational redundancy, the researcher had planned on employing other recruitment strategies. Those strategies included: (a)

announcement of the study through the nationwide network of Guillain-Barre' syndrome support groups with focus on the four support group chapters in Georgia and the four support group chapters in North Carolina (a focus on these areas secondary to distance from researcher) and (b) announcement of the study at medical centers in the United States that have a Guillain-Barre' syndrome Center of Excellence (Appendix E). These strategies were not utilized as the number of responses to the initial study announcement generated sufficient participant interest.

### **Data Collection**

Data were collected through the use of a demographic questionnaire (see Appendix F) and interviews. Qualitative data were collected from participants who self-identified during the consent procedure that they had moderate or severe Guillain-Barre' syndrome. Interviews were collected through in-person face-to-face and electronic face-to-face interviews with the goal of describing the patient's recalled experience with a moderate to severe case of Guillain-Barre' syndrome. All individual interviews were guided by a semi-structured interview guide (see Appendix G) that included open ended questions as well as probing questions. Observations of environmental conditions and participant reactions, including nonverbal communication, during interviews were recorded in writing by the researcher. Public spaces, including libraries and office conference rooms, were arranged for the in-person face-to-face interviews, meeting the participants' need for convenience. Persons who were prohibited by distance from meeting face-to-face were interviewed with online technology.

### **Demographic Questionnaire**

The demographic questionnaire was created by the researcher after a review of the literature and consists of thirty total items. The researcher administered the demographic questionnaire for the participant to complete. For in-person face-to-face interviews, the

questionnaire was a typed form that required the participant to read the item or question and write or select the response. For electronic face-to-face interviews, the demographic questionnaire was emailed to participants. The participant recorded their responses on the questionnaire and returned the form electronically to the researcher. Participants were encouraged to complete all demographic questionnaire items; however, the participant could elect to leave some item(s) blank if they did not desire to answer.

When clarification regarding a response on the Demographic Questionnaire was needed, the researcher discussed this with the participant at the end of the interview. If a response was unclear or an item(s) was left blank and this was discovered after the participant had left the interview, the researcher clarified these items later by email and/or phone contact with the participant.

### **Semi-Structured Interview Guide**

The semi-structured interview guide used to interview study subjects was developed by the primary researcher after performing a review of the literature and considering professional encounters with patients who have experienced Guillain-Barre' syndrome. The guide was comprised of eleven questions and several probing questions dispersed throughout the tool (See Appendix G). The purpose of the interview guide was to generally guide the interview similarly for all participants (Patton, 2002). The interview guide was semi-structured so that the researcher could have flexibility with where the participant might want to take the interview. In the event that the participant did not offer full and comprehensive answers to the open ended questions, the suggested probing questions were present for the researcher to use. The researcher developed rapport with the participants explaining the process for the interview. The goal was to make participants feel comfortable enough to share recollections of their experience with GBS



as recommended by Polit and Beck (2004). Based on the flow of the responses from the participant, the researcher added additional probing and impromptu questions to delve deeper into a component of the participants' experience. When this occurred, the researcher documented these probes to be considered for future interviews. Participants could have elected to not respond to any interview question and could have requested that the interview be paused or ended at any time. This was covered with participants during the informed consent process.

The interviews were preferably held in-person; however, electronic face-to-face (Skype, Go-to-meeting, etc.) were made available based on the distance and associated travel limitations between the researcher and the participant. Polit and Beck (2004) indicate that face-to-face interviews are the most effective method of collecting interview data and are preferred over telephonic interviews because of the quality of the data that can be garnered through these interviews. Efforts to conduct in-person face-to-face interviews included car and plane travel to geographically near locations. It was anticipated that the interviews would last 60 to 90 minutes with a potential follow-up communication that would last no longer than 30 minutes. The length of actual interviews ranged from 35 to 110 minutes. The purpose of the follow-up communication was to clarify any of the participant's responses and perform member checking.

### **Data Management**

All interviews, whether in-person or technology assisted, were digitally recorded. Digital recordings were transcribed verbatim. The transcription was verified to be completely accurate by comparing the typed document to the digital recording. When transferring data via electronic means, such as email, a secure email system was utilized. The researcher's personal computer where any data will reside was password protected.

### **Data Analysis**

The researcher analyzed the data in this study manually. Qualitative content analysis was used as the method for analyzing data obtained during this study. Graneheim and Lundman (2004) report that qualitative content analysis is used in nursing research and has been applied to different types of data at varying levels of interpretation. In qualitative content analysis, the researcher must determine the unit of analysis (Graneheim and Lundman, 2004). For this study, the unit of analysis was the data obtained during one entire interview. Each of the individual interviews was digitally recorded and transcribed verbatim. Transcription of interviews took place after each of the interviews. Once transcription was completed for each interview, the researcher listened and then re-listened to the digital recording of the interview in its entirety and reviewed the transcription concurrently to verify that the transcription was produced verbatim. After ensuring accuracy of the transcription, the researcher read and reread several times the entire interview to begin the data analysis process.

The researcher began data analysis with the collection of data during the first interview. Transcribed interviews were read by the researcher numerous times in order to gain understanding of the meaning of the data. Organizing the data and becoming immersed in it is an essential component of qualitative analysis (Marshall & Rossman, 2006). The researcher reviewed the transcribed interviews to look for statements that revealed a central meaning. Graneheim and Lundman (2004) define a meaning unit as “words, sentences, or paragraphs containing aspects related to each other through their content and context” (p. 106). Once these meaning units were identified, the researcher established a code for that segment of the data. Creswell (2009) describes coding as the mechanism of organizing data into categories and then “labeling those categories with a term [which is] often...based in the actual language of the

participant” (p. 186). Codes were reviewed with the intent of creating categories. Categories are segments of words and/or sentences that shared a common message (Graneheim & Lundman, 2004). Once these categories were established, the researcher evaluated the relationship between the codes and categories to determine themes that were evident in the data. Themes are defined as elements of meaning that are recurrent throughout multiple interviews (Graneheim & Lundman, 2004). Throughout the process of data organization, immersion, coding, and the development of themes, the researcher discussed the data analysis process and findings with the peer debriefer, a doctorally prepared qualitative researcher who was a member of the dissertation committee.

Data also were generated from the Demographic Questionnaire. The goal of the responses to the demographic questionnaire items was to generally describe the participants.

Data were compared to that found in prior studies.

### **Trustworthiness of Qualitative Data**

Lincoln and Guba (1985) reveal multiple strategies that can be employed in order to achieve trustworthiness in qualitative research designs. Trustworthiness is a concept that essentially means whether the reader of the research will find that the research produced findings that were noteworthy and were worthy of review (Lincoln & Guba, 1985). The four key elements leading to trustworthiness include: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Table 9 indicates the tactics that were utilized in this study to contribute to each of the key elements (Krefting, L. 1991).

Prolonged engagement, persistent observation, member checking, peer examination, and triangulation were utilized to achieve credibility in this study. The researcher for this study has had an interest in Guillain-Barre’ syndrome since 2005. The researcher was serving in an

Table 9

*Tactics to achieve trustworthiness*

Criterion	Qualitative Approach	Tactics for use in this study
Truth Value	Credibility	Prolonged engagement Persistent observation Member checking Peer examination Triangulation
Applicability	Transferability	Thick description
Consistency	Dependability	Audit trail Triangulation
Neutrality	Confirmability	Reflexive journaling Triangulation

Note. Adapted from “Rigor in qualitative research: The assessment of trustworthiness,” by L. Krefting, 1991, *American Journal of Occupational Therapy*, 45, 214-222.

administrative leadership position in a specialty hospital where he encountered the family member of a patient diagnosed with Guillain-Barre’ syndrome. Since that time, the researcher has spent time reading and learning about Guillain-Barre’ syndrome and its affect and impact on patients and their families. In addition, the researcher has been exposed to two clinical areas where Guillain-Barre’ syndrome patients have received care. The researcher also has attended two International meetings focused on the education and support of patients and caregivers who have been impacted by Guillain-Barre’ syndrome. The researcher has also traveled to multiple states to meet with participants for the in-person face-to-face interview. The

researcher has also been involved in interviewing participants and the review of data for approximately 6 months. This prolonged engagement and persistent observation has contributed to credibility in this study.

Member checking was utilized to ensure that the researcher understood the intended message from the participant. Lincoln and Guba (1985) indicate that member checking can be done throughout contact with the participant as well as immediately after the interview to correct any misinformation or inaccurate interpretations. This researcher reviewed key information obtained during the interview and clarified any questions about the data obtained immediately following the interview. The researcher also reached out to participants after the interview session, and during the data analysis phase of the study, so that the researcher could clarify any questions or uncertainties about the data that were collected.

Another strategy that was utilized to contribute to credibility was peer examination (also known as peer debriefing). Lincoln and Guba (1985) define peer debriefing as “a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (p. 308). This researcher identified a doctorally prepared nurse faculty with qualitative research experience to serve as a peer in the peer examination process. The researcher met with the doctorally prepared nurse faculty peer, who is a member of the dissertation committee, on a regular and ongoing basis by phone during the data collection and data analysis phases of this study. The purpose of these meetings was to establish understanding about what the data are saying and to ensure that themes that are emerging are being identified.

Triangulation is useful and contributory to several areas of trustworthiness including credibility, dependability, and confirmability. The concept of triangulation was applied in this

study via multiple data sources (data retrieved from interviews, data gleaned from the literature, data obtained through the researcher's written notes during interview observations, and data from information found at the Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International website). Triangulation was also accomplished through the use of the peer debriefing technique where the primary researcher and a member of the dissertation committee member evaluated the data independently and then simultaneously.

Transferability allows an individual the ability to read the results of research and determine if the transfer of the findings is possible in other contexts or within the same context during a different period of time (Lincoln & Guba, 1985). In this study, transferability was achieved by providing a rich description of the study's design and findings. Rich description will allow the reader to make conclusions about the transfer of these findings. The maximum variation in the participants within the sample also contributed to transferability.

The researcher maintained an audit trail and reflexive journal to accomplish dependability and confirmability. The reflexive journal was utilized throughout the research study. The entries in the journal summarized the researchers thoughts initially about Guillain-Barre' to ensure that the researcher had an awareness of these thoughts. Additional entries were made throughout, and after discussions with the peer de-briefer. Entries included emotions that participants experienced during the interview, environmental conditions that the researcher thought were of interest, and various other points of interest to the researcher. The researcher also created a log that was used throughout the study to document decisions made about data analysis.

### **Protection of Human Subjects/Ethical Considerations**

This research proposal was submitted to the University of Kansas Medical Center's Human Subjects Committee for review and approval prior to the initiation of the study. All interested potential participants received a full, written copy of the Research Consent Form (Appendix H) by email. The researcher reviewed the study and informed consent with potential participants using the consent form as a script. Informed consent was obtained in advance of participation and prior to the collection of any data. All participants provided signed written consent either in person or electronically by email. The Research Consent Form defined criteria for moderate and severe Guillain-Barre' syndrome indicating that those who agree to participate satisfy inclusion criteria. Participants received a copy of the Research Consent Form (Appendix H). The researcher obtained a copy of the signed Research Consent Form in order to establish informed consent and the participant's willingness to be part of the study. Participants were identified by a pseudonym to protect their identity. Research materials, including transcription, digital recordings, and any other confidential data were kept secure in a locked location by the researcher. Digital recorders were securely stored by the researcher under lock and key at all times. After transcription, the transcribed interviews were also stored by the researcher under lock and key or password protected at all times and will be maintained for a period of 15 years. Participants were advised that their participation in the study was completely voluntary and that they could discontinue their participation without fear of repercussion or consequence at any time.

### **Summary**

This qualitative descriptive study was utilized to answer three research questions related to patient's recalled experiences of care and caregiver interactions, environmental conditions in

the care environment, and knowledge level about Guillain-Barre' syndrome. This research looked to better understand what the patient recalls about encounters during an acute episode of moderate to severe Guillain-Barre' syndrome and what learnings could be shared with educators and clinicians to enhance the care provided to patients affected by this illness. The participants were patients who had been previously diagnosed with moderate to severe case of Guillain-Barre' syndrome. Inductive content analysis was utilized to analyze the data to establish themes.



## **Chapter Four: Results**

The purpose of this qualitative descriptive study was to gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome. This chapter presents the results from data collected in in-person face-to-face and electronic face-to-face interviews. The five themes and 14 subthemes that emerged from the data are presented, including a rich description of the participants' recollection of events and occurrences during their illness with Guillain-Barre' syndrome, using their own words. Chapter Four also presents a description of the 14-participant sample based on their responses to questions on the 30-item Demographic Questionnaire.

### **Sample and Setting**

There were a total of 89 individuals who either called or emailed about participating in the study. Of the 89, there were 65 females and 24 males. These numbers closely align with the final sample percentages for the study as noted in the following: Interested individuals (female 73.0%; male 27%); Sample (female 71.4%; male 28.6%).

One person was deemed ineligible for this research study because of age. Specifically, the individual was seven years old and resided in Australia. The researcher was contacted via email by parents who inquired about the study. Three other persons were deemed ineligible for this research study secondary to the individuals continued to require hospitalization and in one case was still intubated requiring mechanical ventilatory support. Again, the researcher was contacted by email or phone on behalf of these individuals by members of their family.

If individuals were deemed eligible, the researcher emailed study related information which included a short electronic note from the primary researcher, the formal research study announcement, and the Research Consent Form. Interviews of participants began after the

participant signed the Research Consent Form and had a phone conversation with the researcher to review the Research Consent Form and field any study related questions.

The final sample consisted of 14 participants who self-identified as having had a moderate to severe case of Guillain-Barre' syndrome. These fourteen participants were interviewed either in-person face-to-face or electronically face-to-face (via the Internet video software, Skype) between January 2015 and March 2015. Participants were located in eight states including: (a) Alabama (2 participants), (b) Arizona (2 participants), (c) California (1 participant), (d) Florida (1 participant), (e) Georgia (4 participants), (f) Mississippi (1 participant), (g) North Carolina (2 participants), and (h) Texas (1 participant). The researcher conducted nine in-person face-to-face interviews in five states including Alabama, Florida, Georgia, Mississippi and North Carolina. The remaining five interviews were conducted electronically face-to-face utilizing Skype.

There were 10 female and four male participants. Participants' ages ranged from 16 to 76 at the onset of their illness with Guillain-Barre' syndrome. Twelve participants identified themselves as Caucasian/white, one identified as Scots/French American, and one as Hispanic Mexican American. Ten of the participants were married at the onset of their illness with Guillain-Barre' syndrome and four were single. Table 10 depicts other key demographic information.

Of the 14 participants, all had required hospitalization for care related to Guillain-Barre' syndrome. Participants reported being hospitalized between five and 405 days. Table 11 provides a summary of the number of days that participants reported being hospitalized. Twelve of the 14 participants reported being admitted emergently. Ten participants received hospital care in an intensive care unit. Twelve reported that they were unable to ambulate at all while

two reported that they could ambulate but ambulation was significantly impacted. Responses were consistent with those related to lower extremity paralysis (LEP) where 12 participants responded that they did have paralysis and two responded that they did not experience LEP.

Table 10

*Participant Demographic Data*

Demographic Characteristic	Response Options			
Gender	Male		Female	
	4 (28.6%)		10 (71.4%)	
Race	Caucasian (White)		Other	
	12 (85.7%)		2(14.3%)	
Marital Status at Onset of Illness	Single		Married	
	4 (28.6%)		10 (71.4%)	
Education	High School Graduate	College Graduate with Diploma	College Graduate with Bachelors	College Graduate with Masters
	3 (21.4%)	1 (7.1%)	6 (42.9%)	4 (28.6%)

Table 11

*Number of days spent in hospital*

Range of days	Number of participants
< 10 days	3
10 – 30 days	3
31 – 60 days	6
61 – 90 days	0
91 – 120 days	1
121 – 150 days	0
> 365 days	1

Table 12 presents the age of the participants at the time of their illness with GBS as well as their current age at the time they were completing the Demographic Questionnaire. Their illness with Guillain-Barre' syndrome occurred between the years of 1979 to 2014.

Table 12

*Summary of current age ranges*

Age Ranges	Number Currently in Age Range	Number in Age Range at Onset of GBS
10 - 19	1	1
20 - 29	1	2
30 - 39	0	1
40 -49	0	2
50 - 59	2	3
60 - 69	5	4
70 -79	5	1

Note. GBS=Guillain-Barre' syndrome

Participants were queried regarding any preceding illnesses or immunizations that occurred before the onset of their illness with GBS. Table 13 presents the data related to immunizations and illnesses. All participants denied having any family members that had been diagnosed with Guillain-Barre' syndrome.

### **Themes and Subthemes**

Data from the 14 participant interviews were analyzed. The analysis process included the researcher becoming immersed in the data. This was achieved by reviewing transcripts for

Table 13

*Summary of data related to illnesses and immunizations that preceded participant's diagnosis of Guillain-Barre' syndrome*

	Yes	No	Unknown
C. jejuni	0	12	2
Other Illnesses	6	8	0
Immunizations	7	6	1

Note. Participants were asked "Were you told that *Campylobacter jejuni* preceded your illness?; Were you told about any other illnesses that may have preceded your GBS, Did you have any immunizations within the 6 months prior to your GBS?"

C. jejuni=*Campylobacter jejuni*

accuracy while listening to the digital recordings of the interviews. The researcher listened to each of the recordings a minimum of two times. The researcher verified that all interviews were transcribed verbatim. The researcher then read and reread each of the transcripts several times. The transcripts were put into table form allowing for the identification of meaning units, codes, and formulated meanings. While this process was occurring the researcher had weekly dialogue with a member of the dissertation committee. The purpose of the weekly meetings was for the member of the dissertation committee to serve in the peer debriefing role. Peer debriefing is important step to establish trustworthiness. This process was to ensure that there was understanding regarding what the data were saying and to ensure that themes that were emerging were being identified. From this process, five themes and 14 subthemes emerged. Table 14 lists the themes and associated subthemes.

Table 14

*Themes and Subthemes*

Themes	Subthemes
Theme 1: Physical manifestations of GBS	ST1: “ A Strange Sensation” ST2: A Rationalizing of Symptoms ST3: “The Downward Spiral” ST4: Pain and Fatigue
Theme 2: Attitudes and Emotions	ST5: The “Emotional Rollercoaster” ST6: “Attitude is Everything” ST7: Seeking Independence ST8: Concerns for Others
Theme 3: Knowledge and Awareness	ST9: “No Earthly Idea what GBS was” ST10: A Desire for More Knowledge
Theme 4: The Value of Peer Contact	
Theme 5: Care Concepts	ST11: Staff Knowledge and Available Information was “Remarkably Absent” ST12: Personalized Patient Centered Care ST13: Communication with Caregivers ST14: Impact of Achievements

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Note. ST=Subtheme

**Theme 1: Physical Manifestations of Guillain-Barre’ Syndrome**

The first theme that emerged from the data was the physical manifestations that participants experienced during their acute episode of a moderate to severe case of Guillain-Barre’ syndrome. Participants described the manifestations of physical symptoms at the

beginning of their illness, what they thought of these symptoms, and the subsequent progression of symptoms. There were four subthemes related to physical manifestations of Guillain-Barre' syndrome including: (a) *"a strange sensation"*, (b) *a rationalizing of the symptoms*, (c) *"the downward spiral"*, and (d) *pain and fatigue*.

### ***"A Strange Sensation"***

The interviews began with a question to participants asking them to share what initially occurred at the beginning of their illness with a special focus on symptoms and how they felt during the time when they recognized physical symptoms. Most participants described the initial symptoms that were manifested as strange or odd sensations or peculiar feelings.

One participant revealed "I started feeling tingling in my feet" and "I couldn't sleep because my – I just couldn't get comfortable. My legs are feeling weird, and they would start cramping up too" and "My hands are just feeling a little weird". As the symptoms progressed, this participant further stated, "So it was strange because I couldn't feel things. But when I could feel something it was – it was like extreme – multiplied". Another participant stated, "I had difficulty balancing. And I kept getting weaker and weaker during the day. And had, kind of, just unusual weird sensations". Another participant discussed symptoms that he experienced while on vacation. He revealed that he "had been on vacation up in New England during July of 2006. And [that he had] noticed ...when [he was] in Boston, [that he] had a little weakness in [his] legs when walking around, which was really odd...because [he] was in pretty darn good shape". Several participants noticed these symptoms during normally planned routine activities. For instance, another participant had plans to care for her grandchild while her daughter was at an appointment. When awakening that morning she reported that "I couldn't move my legs normally....it was like I couldn't -- I had to sort of slide my feet. It was like I couldn't --couldn't

pick them up...I said: There's just something strange going on...I can't walk correctly".

Another participant said "I felt – I felt like my legs weren't there almost". Yet another participant stated "I didn't feel great, but in the morning I only drank coffee. And that morning I thought: Well, I'm going to drink a little bit of orange juice. So I went to the refrigerator to get orange juice, and I had difficulty opening the lid. And I thought: That's strange. You know, just in my mind, I thought that was strange [then later]...my arm feels funny...my arm felt strange; and it was my left arm". One of the participants also described the sensations that she was having as an odd and strange feeling. "I had an inkling that something was wrong because we were shopping for another piece of luggage. We were getting ready to go on this trip, and I had a shoulder bag that I couldn't keep the shoulder bag on my shoulder for more than 10 seconds, and then I wanted to switch it to the other shoulder. I thought: That's odd...[and then at work] you always have to sign your initials anytime you do anything, sign your initials, and it was getting difficult to sign my initials. I thought: Well, this is strange" and when the participant arrived at the hospital to be evaluated she reported that "it was like I was walking six inches above the floor. It felt like I could fall at any minute. It was a strange sensation".

Likewise another participant described her symptoms as strange and peculiar. This participant was talking with her husband and "said to him: It's funny. I have a little oval area on my left thigh that feels like somebody had given me a shot of Novocain. It's just, kind of, numb...peculiar". Later that night after going to bed, this participant awoke "about midnight, and...had to go to the bathroom. So [she] got up and when [her] feet touch the tile floors, [she] thought: This feels strange...[she] felt like [she] had a sock on [her] foot, which [she] didn't...But I couldn't understand why that felt so strange." Another participant used an analogy to describe her symptoms where she related the sensation in her legs to that of bugs crawling on



her. She stated “a couple of days before, I was driving, and I felt like I had ants on my legs; and I kept reaching down trying to get them off; and there was nothing there; it was just the sensation of ants on my legs...I had the feeling of bugs crawling all over me”.

### ***A Rationalizing of Symptoms.***

When participants initially started to experience symptoms (that would later be recognized as the onset of Guillain-Barre’ syndrome), they tried to explain away the symptoms. The participants attempted to relate these symptoms to normal everyday activities and/or occurrences. Participants thought that perhaps these activities and/or occurrences could have precipitated the symptoms that they were experiencing. They believed that these normal everyday activities and experiences contributed to the manifestation of symptoms. One participant discussed having a possible sinus infection prior to GBS related symptoms. She sought medical evaluation and was prescribed an antibiotic. When she experienced a tingling sensation in her lower extremities, she “started thinking maybe this was like a side effect of the medication. So I saw the doctor on Friday, and she took some blood work. And she told me she didn’t think it was the medicine, but I was pretty sure it was the medicine; so I stopped taking it”. “I didn’t take it very seriously. And looking back, I don’t know what I was thinking. That it would just go away. Or if I just stopped taking the medicine, maybe it would be okay...and I guess since it wasn’t that bad, I just thought it would go away”. Another participant reported that she had had an ear infection and had taken antibiotics as prescribed by her physician. This led her to believe that her symptoms were related to the ear infection. She “figured it was like an inner ear infection that had come from the earache. I didn’t think much about it”. Similarly another participant revealed that she related her symptoms to either the effects of durable medical equipment that she used at home or an injection that she received for back pain. “When

I got up in the morning—I have a machine that sort of vibrates and helps my legs, just the blood start flowing—and I got off of that machine, and I could not move. And I thought maybe the machine had done something, you know because it does shake the legs a lot. So I got off of that machine, and I couldn't move my legs normally.” After talking with her son, who is a nurse, she also thought that it may have been related to an injection related to lumbar arthritis. Her son “wanted [her] to go on to the hospital then. And [she] said: No. [She] said: I think, maybe it's this shot I've been having in my back...So, I thought it was that, and I said: No, I'm going to wait and go to the doctor on Monday”. Another participant commented that he had been healthy all of his life and had never really been sick. He revealed “I was just a beefy guy, and I had been since college. But I noticed a weakness in my legs, and that's the first time I'd ever noticed that. It was no big deal. I thought: Now I'll have to see my doctor when I get back [from vacation]”. Another participant related her symptoms to a busy schedule. “I had gone to watch a movie. I sat down and a few hours later, I stood up. I was really unsteady. I noticed some pain in my legs that day, but I'd been pretty busy; so I just thought it wasn't anything to be worried about”. Another participant had gone to visit family in New York when she began to have symptoms. She indicated that “I went to New York...I'd been there approximately 10 days, and I did have what I would call an upper respiratory problem...I'll preface that by saying when I go to New York, I always would get sick, so I did not think that was unusual for me to be that way”. One participant physically was very active and she related the symptoms that she was having to all of the physical activity that day. She “went to [her] usual 6 a.m. power yoga class...and then when [she] got home it was a beautiful spring day, and [she and her] husband...had cleaned off [their] screened porch: moving furniture, mopping floors, and doing all that physical activity...and then [she] had some running around to do in the afternoon...that evening...attended a lecture with an

older friend of mine. It was at a church. We sat on wood pews. And it was over at about 8 o'clock. And when [she] stood up, [she] went eewwhh. [Her] back was hurting because sitting on [those] wooden pews...and, [she] thought: I have hurt my back somehow doing all this stuff I've done today. And mentally said to [herself]: Aha...60 is catching up with me". Another participant had children and discussed her level of fatigue. She said "I just had no energy whatsoever to...to do anything...Life goes on when you're a mom".

### ***"The Downward Spiral".***

Most participants described the pace and progression of symptoms. Generally, symptoms worsened during the initial period of the illness and often included pain and fatigue as well as other physical symptoms. A participant said "before I was intubated, there was that slow progression of down – the downward spiral". Another participant reported that "I had to travel to L.A. for work, and I started getting these massive headaches the week before...I took a few days before to actually do some traveling [in L.A.], and I couldn't make it very long in the day. I would get to the hotel and just fall asleep. And I'd be extremely tired, and I'd get these headaches again". "Over the weekend—it got worse...I was starting to feel numbness in my mouth...I woke up and couldn't feel my toes. Like I would wiggle them whenever I woke up, and I couldn't feel them; so I panicked, and we went to the hospital". "I feel like very quickly after that, I mean, maybe like two, three days in the hospital, I couldn't walk anymore". "It felt like everything went downhill". Another participant described how his symptoms quickly progressed. "Well, a couple of days later [after my "wicked" eye infection] get up to go to work, put on a pot of coffee—and I'd go to work early in the morning....and the night before I'd felt a tingling in my toes, and we called the emergency room. The doctor on duty said: Ah, don't worry about it. Just come on in tomorrow if it's any worse, so I woke [my wife] up and said:

Look, I'm going to put on some coffee, take a shower, get dressed, and I – then you can drive me to the hospital...and realized all of the sudden that, whoa, I'm unsteady on my legs. And I'm about ready to lose my balance and I feel weak...went into kitchen, poured a cup of coffee and realized if I didn't lay down on the floor, I was going to fall down...and [my wife]...called the ambulance". Yet another participant also experienced a progression in her symptoms. She revealed that my legs "went from a little bit of weakness overnight to, pretty much, complete non-being able to use them". Another participant discussed her progression of symptoms that have now led to her permanent disability. This participant went to the physician's office for care. The physician's office called for emergency support and transport because they felt this participant was having a stroke. The participant reported that "they called the paramedics to come and get me and take me to the hospital. And I'm lying on the table; three guys came in with their thing (backboard for transporting individuals up or down flights of stairs). Of course, they have to put you on a funny kind of stretcher to get you up the steps [from the doctor's office that was in the basement of this building in New York]. And it was lying there on the floor. And I just started to step off of the examining table – the way you would normally do – and when I stepped off, I just fell flat on my face in the floor. That was on the 19<sup>th</sup> of November at about 3 o'clock in the afternoon. Never stood up another day in my life. I just – that's how fast it hit me". One participant had a similar experience with the rapid progression of symptoms. She stated "that strange feeling was sort of spreading...I was losing function per hour – I mean, probably per minute...I was unable to do more and more as the time progressed...So, within 24 hours, I couldn't do anything".

### *Pain and Fatigue.*

Most participants experienced moderate to severe pain during their illness. Many described that minimal touch aggravated the pain where a few participants indicated that rubbing of the upper extremities actually helped with the pain. Other treatments such as hot baths or ice packs were also mentioned as being effective for pain control in some patients. Pain was a significant complication for most participants. In addition to pain, participants also often described ongoing fatigue as part of their acute illness and also in recovery. [My legs] “were just like these blocks of pain. And I do remember my feet feeling like they were on fire...so the only symptoms I had were weakness and pain at first”. A participant indicated that “anytime I would try to cross my arms, cross my legs, I would just be in horrible pain. So I stayed awake all night...in the morning hours, I just got my husband up around 4:00, and I said: I’ve got to go back to the hospital. I said: I am in so much pain—plus four days of not having any sleep”. Another participant revealed that he also experienced severe pain that required multiple analgesics. “I had – when I was regaining my muscle – muscle functions, I had a lot of pain...I had really extreme pain in my muscles...and I had a lot of pain in my arms. It just felt like somebody was pulling the muscles off. It was excruciating pain in the arms, in particular, and in my face”. Another participant described his intense pain as the feeling of muscle tearing as well. He stated “one morning, you know how you stretch after you wake up? I was doing that. And I can’t imagine what it would feel like to have flesh or a muscle tear, but it almost felt like there was some sort of tear that took place, kind of, between my shoulder blades. Maybe just a hair higher than that. And from that point on, I just kept having this pain across the top of my shoulders. And it just kept getting more and more intense. And eventually, it started to radiate down my arms”. Another participant also used the term excruciating to describe her pain that

involved the shoulder. “I was having pains that would start in my back and shoulder and then just run down my right leg; excruciating...I remember it almost like clockwork. I would get to a certain part of the afternoon, and then I would – I could feel it starting, like below my shoulder blades...and then...it was just going to travel through my body down my right leg; and I would just be in constant pain. It was very uncomfortable”. Another participant described her pain in a similar fashion. The pain “was emanating from the base of my spine, the very bottom. And probably, by this time, I was feeling pain down both legs – shooting pain down both legs...[on] a scale to 10...I would say [my pain was a] nine...I went back to bed and I was really writhing, just rolling around on the bed”.

Participants also described feelings of fatigue. One participant said “it would take too much effort for me to cut my food and eat it. So my mom would cut my food, and they would basically just feed it to me. Because it took all my effort to, basically, chew; and then after I would eat, I would be exhausted”. Another participant said “Just that tiredness level of whatever my muscles were doing, they just couldn’t do it. Which was interesting. And I still have fatigue”. She acknowledged the staffs’ awareness of her fatigue when she stated “But they were very conscientious of working with me, knowing that I was extremely tired, extremely fatigued”. Other participants indicated that staff were not aware of the fatigue in Guillain-Barre’ syndrome and subsequently pushed them too hard in therapy. One participant who went to inpatient rehabilitation stated “the people are very nice, but they were, sort of, of a no pain no gain philosophy. And I would tell them: That's not what works with Guillain-Barre. And they were in charge. They didn't believe me. So I just told the doctors I wanted to get out of there. I felt like I could do better at home”. She further stated “I would say, you know, I'm exhausted by this. I need to quit. [Rehab was then] like: Oh, just a few more steps”. Another participant

said “And I was tired. My energy level. Actually, my energy level got worse as the time went by, the weeks afterwards”. One participant also indicated that his fatigue progressively worsened over the course of the day. He stated “And then as the -- like I said, the day went on like, you know, [I became] weaker and weaker”. Another participant stated “I mean, I was really, really weak”. A participant reflected on his fatigue during vacation before he knew that he would become ill with Guillain-Barre’. He stated “I just felt a little fatigued and had to sit down. That first part, when we were on vacation, usually it's [my wife] that does it. This time it was me”. One participant called this issue “the tired factor”.

## **Theme 2: Attitudes and Emotions**

The second theme centered around the attitudes and emotions that participants experienced during their course of illness encompasses four subthemes. This theme illustrates the wide range of emotions that participants encountered; how having a positive attitude impacted mental well-being and was a useful coping strategy, how independence was desired, and how participants experiencing significant levels of personal disability had concern for their loved ones. The four subthemes included: (a) *The “Emotional Rollercoaster”*, (b) *“Attitude is Everything”*, (c) *Seeking Independence*, and (d) *Concern for Others*.

### ***“The Emotional Rollercoaster”.***

Participants described many emotions as a result of being diagnosed with GBS and the subsequent care that was required. One particular participant stated in reference to the emotions that she encountered, “there were so many. Frustration that I couldn’t figure out what was wrong with me. Guilt because I was taking so many drugs. There was...a not knowing what was wrong with me was, um, just heartbreaking. A frustration when I fell at work, I laid in the doorway of my job, and I just cried”. Another participant experienced fear when she was told

about her diagnosis of GBS. She said “I had no idea what it might be. I was scared. I was told I was faking it...I felt like – honestly, I was 16 at the time, and I felt like my life was over. I was a cheerleader, and I knew that was going to be over now. And just all of the stuff was happening at once within a few days, and it was terrifying”. This participant went on to say “it was just strong emotions through the whole thing. I felt like for almost a year my life was an emotional rollercoaster because of it. First, it was just scared, confused, mad, just really angry that this is happening to me. And then in a bit there when I started, sort of, taking my first steps and doing a little bit more progress, it was determined and hopeful. The fact that it happened so fast. There was no warning. It just happened. And the fact that it was so dramatic, It was, like, the sky was falling all of a sudden”. Participants also experienced fear. “The biggest challenge was fear. Fear. What’s happened to me? Am I going to be okay? I didn’t think I might die, but I just – you know, I’ve been an active person [and] I was afraid that I wouldn’t be able to do those things again. Or just immediately, I was afraid I couldn’t even stand up on my own two feet, you know...I think that was it. Just the fear and worry about the future”. This participant also described a wide range of emotions. “The first day as those little things were happening, I was just...dismayed, I guess. You know, what’s going on?...then the emotion of fear when it knocked my legs out from under me. I never had anything similar to that in my entire life. You know, to be that disabled, that, or very rapidly. Frustration. Just because I couldn’t do...do what I wanted to do. I couldn’t make my legs...motivate”. Another participant described the wide range of emotions that she experienced. She said “when I got to the hospital, [I felt] more curious. What’s going on? What’s causing this? Glad that I’d arrived someplace where somebody could help me. Relieved a little bit. I guess when I was admitted to the hospital that they were glad they didn’t send me home...and after the ICU experiences, I began to awake and



learn more about what I had. Then, I was scared. You know? How was I going to earn a living? How was I going to...what was I going to do with myself? You know? What if I was crippled or paralyzed?...those were legitimate worries. Those were all reasonable things to be scared about".

Another participant also experienced a range of emotions including "initially...frightened, obviously. You have no idea what is happening to you...And, so fear of the unknown. A little frustrated that you can't overcome it. I like to work my way through things, and there's no working your way through that one...Elation, I guess. When you're finally going to get out of the hospital...Anger over the care at rehab. And anger with the doctors not being able to listen...doctors are amazingly poor listeners. And gratitude. I mean, geez. I don't know. You know, it's one of those times where thanks is not adequate, but it's all you got". One participant described being upset with staff regarding the use of a fall alert monitor. She revealed that "my worst experience about this was having the alarm on my bed. And you know hearing the voice that come over the intercom saying: Do not get out of bed! And to be yelled at. I mean that's the only way I can put it. You know they weren't really mean, but you know, being told, 'Don't get out of bed', you know, all of the time just kind of ticked me off a little". A participant also described periods of being agitated. She stated "I'd have a little temper tantrum—I'd call it. Not seriously, but I would just in my – you know, I'd just grit my teeth and clench my fist and go...why did this happen to me? I'm so tired of this! I'm so tired of this! So, you know a little self-pity". Another participant described her emotional response that occurred secondary to the care that was provided to her. She stated "when I could still walk they bathed me in the shower, which I thought was horribly traumatizing. Because, you know, I was 25. And being bathed by someone was, like, extremely embarrassing. So that was, I think, the first day of, like, my traumatic – when I say my traumatic experience. When I started crying like every day. That was

the first day...maybe a day or two later is when I couldn't walk. So then they came in and gave me a sponge bath. So I ranked that as even worse. It's just very – It felt very demeaning because, you know, I was still young and somebody here bathing me on my bed. I thought it was terrible". One participant commented "Emotionally...I will always feel impaired. I will always...remember who I used to be". This participant felt like her psychosocial needs were not met. She went on to say "the mental process of going through this illness was never addressed, really, except by me".

***"Attitude is Everything".***

Many participants discussed how maintaining a positive attitude helped them maneuver through the significant emotional challenges of this illness. One participant stated "Your life isn't over. And I know it seems like it but it's not. It's going to get better but your attitude is everything. Your attitude will make or break this thing for you". Another participant stated "I've always maintained a positive outlook somehow. I don't know. What else could I do? I mean, all I could do was do what I could do today. And hope that tomorrow was better. You know? And I...I didn't cry or anything, and I didn't get depressed; I wouldn't say that I ever really got depressed...I had one child, a daughter, [who] died [from a heart condition with] no warning...no hope. Gone within five minutes of keeling over. In that perspective, this wasn't worse. Guillain-Barre' was not worse than losing my only child. And I grieve...[having GBS] is grief of another kind". Another participant said "know that there's a light at the end of the tunnel. Another participant stated "I was depressed but I worked through that. I likened my former healthy self to be a 7-foot ladder, and GBS had made me ...I was now a 5-foot ladder. I remembered what I used to do with those two feet that I'd lost. All my functionality that I lost was in that two feet of the ladder. That's the best way I can express it in the fewest number of

words. But my 5-foot was now normal. Whatever's left will be enough to have a good life".

Another participant said "It may not be the light that you're hoping to see, but at least, you know there's light".

### ***Seeking Independence.***

Many participants described their need for increased control and independence. One participant said "I finally – I decided in my mind that I needed to create a deadline, or I needed to – I needed to take charge over something I obviously had not control over. But I remember pushing myself up, putting my arms on the bed, and saying: Listen, we've been here for, you know, 27 hours. We came here looking for health care, and all you have done is talk. I said: If you don't give me some treatment within the next three hours, we're going to leave. How I thought I was going to make good on a threat, I have no idea. But I – I decided that was all I could do was give them a deadline". Another participant stated "occupational therapy helped me a lot because...it was nice to learn how to adapt, to even where I could – I could do some stuff by myself when I was In the hospital...being able to get into the wheelchair and brush my teeth in the morning was a big deal". Another participant stated "Well, little by little, you know things got better. I mean, I can remember being so excited at home when I had to – I could actually get myself a cup of coffee and walk across the room without a walker...with a cane...and sit down in a chair, and do that all by myself. I thought that was just ...a major feat".

### ***Concern for Others.***

Several participants expressed concern for their loved ones while they were hospitalized with GBS. A participant stated "But I do remember...there was – the type of beds they had for parents – because my mom stayed 24/7 – and I really liked the fact that she had somewhere to stay. Made me feel a little bit better. Like, almost like I wasn't being selfish because I asked her

to stay. Because she was going to be okay, too”. Another participant was concerned for her husband. She stated “I didn’t go to sleep when I first came to the hospital because my husband had to go to work, and I said: No. I’m fine...I’m in the perfect place. I said: Go home. There’s nothing you can do.” This participant later shared “Your sisters are coming. They’re going to take care of you. That made me feel really good. My goodness that hit a nerve [participant was sobbing]. I knew – they could take – they would come in there – I said: They’re going to feed; they’re going to cook; they’re going to clean. I said: you are not going to have to do anything. They were doing what I couldn’t do”. A participant also expressed concern for her husband’s well-being. She stated “I was worried about my husband too, I guess. That was a part of it. All my family – I’m from a big family, but everybody lives someplace else...But as I got better, I worried about him and, you know, where he was getting support.

### **Theme 3: Knowledge and Awareness**

The third theme concerns the knowledge level of participants at the beginning of their illness and the desire that they had for additional information from caregivers and other resources. The analysis of data related to knowledge and awareness of Guillain-Barre’ syndrome resulted in two subthemes including (a) “*no earthly idea what GBS was*”, and (b) *a desire for more knowledge*.

#### ***“No earthly idea what GBS was”.***

All participants revealed that they had no knowledge of Guillain-Barre’ syndrome prior to their illness. One participant stated “Nothing. Before they came in and said the words GBS, Guillain-Barre’, I had never heard of it”. One participant stated “Zero. I’m sure that I had been asked every time I got a flu shot if I’d ever had it, and I said no because I probably didn’t even know how to pronounce it. In fact, I had to have people write it down for me. I remember when

I was in ICU, just so I knew what I had”. Another participant stated “I mean, absolutely nothing. I didn’t even know that it had existed, and...and even when she told me on that Monday that’s what they thought it was, I still thought: No. I don’t think that could be it.” Another participant recognized the name Guillain-Barre’ syndrome but still did not have knowledge regarding what occurred as a result of this illness. One participant revealed that “I think that I had heard about it when they talked about it sometimes in relationship to flu shots. But that was – I had no earthly idea what it was”. Another participant stated that when she heard Guillain-Barre’ syndrome that that was “Greek to [her]” and that it sounded like “gobble-de-goop to [her] at the time...[she had] never heard of it [before]”. Another participant was a retired registered nurse. She stated “I had not worked in a hospital for a number of years. And I had never taken care of a patient with Guillain-Barre’...I didn’t know anything about it”. Another participant revealed that she did not have an awareness of GBS and the impact that it could have on her physical function. She stated “Absolutely nothing” when asked about what she knew about GBS before her diagnosis. She went on further to say “And honestly, the neurologists that were filtering in during those first six days I was in the hospital, I wasn’t taking it too seriously”. Another participant revealed that “I didn’t know a thing about Guillain-Barre’, and really we were scared of what it was. Like I said, I thought, maybe, it was ALS. And I had no idea that it was – you know that it might be Guillain-Barre’. I didn’t even know what Guillain-Barre’ was”.

### ***A Desire for more Knowledge.***

Participants used a variety of ways to learn what Guillain-Barre’ syndrome was and what to expect in terms of the prognosis for this illness. Information regarding strategies that participants used to increase their knowledge and awareness of Guillain-Barre’ syndrome was gleaned from the interview guide question where participants responded to the question, tell me

about how you learned about GBS after you were diagnosed with the illness. Participants also commented on the value of this knowledge in terms of the outlook for the future. One participant stated that she would have liked “someone who might’ve brought me or my husband some information about it. Somebody who – maybe the neurologists to have taken five minutes to give us a little rundown on what this was...help me understand what’s happening to me. Help me understand what I can expect. Or not.”. Another participant stated “The duty nurse – one of the duty nurses at ...the hospital told my wife about the Guillain-Barre’ Society. And she went online and requested the information. They sent the information out”. Another participant’s family helped to collect information to assist the participant and the family better understand the illness. This participant’s “parents had come to stay with [her] to help [her], and [her] dad...contacted the CDC – Centers for Disease – and that’s where he got the information...and...[her] parents got [her] the book...”No Laughing Matter, “ that Joseph Heller had written...and my mom would read it to [her]”. A participant’s mother also assisted her with researching the illness. She stated “my mom mostly. Because most of my – most of the beginning of the hospital stay, I was pretty out of it on pain medication...So, I didn’t look up anything. My mom researched a bunch of stuff and tried to use that to help me to help explain what was going on, and to help, you know, comfort me about it”.

Many participants commented on their use, as well as their families use, of internet based resources to learn about Guillain-Barre’ syndrome. One participant stated “the Internet. I had my iPad with me and my iPhone with me...my husband went home and did some research on it and came back and told me. But I don’t think I was told very much by the people in the hospital. I don’t remember that being the place where I learned – I learned anything more than what the diagnosis was...I think there’s something good on Wikipedia. I think the CDC had a good

explanation on their website”. One participant stated “after I got home, of course, I got on the Internet, and I looked it all up. I learned how to spell it and pronounce it and a lot about it. And at one – at one point, I found a list of 25 possible causes, and it included Lyme’s Disease, and I don’t remember all. But for every single one, there was a no for me”. Another participant also stated that my research, “It was all online”. Another participant stated “my daughters – my three daughters flew in, and they were there with my wife. And, uh, they are all very techy, so they were looking up everything they could find on the Internet about it at the time”.

Some participants did not find the information on the Internet to be helpful. One participant stated “I started looking things up. And basically, everything that we saw online was very negative. So, we were just trying – I was just trying to push it aside and say this is not what I had. And then all the horribly negative stuff I found online. So it was not a very positive learning experience, I would say. I really wish that there was something that just, kind of...was a little bit more helpful...It’s very difficult to, kind of, look forward and be like: Oh I’m going to be okay”. This participant was not opposed to utilizing the Internet for research purposes related to this illness but would have found it more beneficial if the information found online was more balanced.

Several participants were not aware of the Guillain-Barre’ syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International or the educational and advocacy resources that they have available. One participant stated “I only learned about the foundation about two, or maybe three years ago through another person...who had a GBS diagnosis...and it was through them – they had brochures and such”. Another participant discussed the value of the resources provided by the GBS/CIDP Foundation International. She stated my daughter “contacted the national organization...and they must have sent [the books

out] fast because they sent a couple of books...and as soon as I did wake up enough to know, you know, who I was, she would set there and read that stuff to me out of the book. So, that's how I learned about it was from my daughter. And what I thought, I guess, was a saving factor was, you know, almost everybody gets over it".

Many participants expressed the desire to have more information about their illness. In addition, participants commented on the value of this knowledge and the impact that it had in terms of their future outlook. When asked, are there things that you know now that you wished you would have known when you were diagnosed with GBS, one participant responded "well, certainly more information. You know, what is it? What does it do to you? And what are the – what's the prognosis? More like that". Another participant stated "once I had a name to what was going on, it was a little bit better because I could hear that you have a chance of getting better, you probably will get better, and it will be okay, it will all be over soon".

#### **Theme 4: The Value of Peer Contact**

The fourth theme reveals the importance of peer contact. Participants commented on the value of being able to talk with an individual who had also been ill with Guillain-Barre' syndrome. This provided the participants with hope about recovery and the future. Participants described that information coming from an individual who had been through the illness would have been perceived differently than the information coming from staff. Information from individuals who had experienced GBS would have been more impactful. A participant stated "I'd had a friend who she actually has been through GBS as well, and the chances of it – because I went to a very small school were so rare – and so she helped me a lot because she was up walking again". Another participant was actually visited by a surgeon who had been personally impacted by GBS and he described the benefit of this interaction and stated "I think most of the



information I got was from a surgeon at [the hospital] who he, himself, had Guillain-Barre' and was no longer able to do surgery because of lost finger dexterity; but he was able to maintain a regular medical practice". Another participant stated "I realize now that that can be very beneficial to have someone who – who might've gone through something similar". Another participant agreed and furthered her comments by suggesting a process that would be developed to alert peer counselors as you would alert any other adjunctive therapy personnel. She stated "wouldn't it be nice if it would – if it was just as possible for them to have a peer counselor come in, or somebody like me – somebody who has had Guillain-Barre' or has had a family member whose had it who could come in and give some reassurance. I don't think it would be possible for health – you know, for nursing staff necessarily to – I mean, they can't say there should be a nurse in every hospital that's had Guillain-Barre. That would be kind of goofy. But I think a peer counselor ought to be offered just as readily as they'd offer Reiki or aroma therapy. It's seen as an alternative kind of health care intervention that could be really beneficial to a patient. I think it ought to be just – especially for a rare disorder. And if it wasn't readily available, I guess that would be just a dream, but I think it is. I think all somebody would have to do is call the Guillain-Barre Foundation. And they would have found [another GBS patient], who is [in my state/area]...or they would have found somebody that's on their registry in this list and call them up. Say: Are you willing to go see somebody in the hospital? That ought to be routine...peer counseling, I think, is incredibly important for something that's a rare disorder".

Another participant shared similar sentiments. He stated "If you ever have anybody in here, in this condition...I'd be happy to come over, and I'll shoot the breeze for a little while. And tell them, you know, you can get better, you know? And I think if I would have heard something like that from somebody who had been through it, rather than a caregiver giving it to me, I think

it would have had a lot more impact on how I would have perceived everything. I really do. The issue [with hearing it from a caregiver] was probably a lack of credibility on my part”. Another participant stated “And just trying to find out from other people’s experiences because like I said, the doctors, obviously, can’t tell me: Oh. In three weeks you’ll be fine. Because they don’t know. So we were just trying to find things – more of other people’s experiences and how quickly they recovered or what they did to help them recover”. One participant had conversations with two GBS peers and also used online resources to connect with others who had had GBS. She states “There were two people who had GBS...One was this man. He had GBS and now he was working and he was back at work and we related and talked. And the other one was Miss L...She still calls me every now and then. Just came by to talk and visit with me. And that was very nice, and that was – and they told me a lot about...recovery, I guess. Recovery was possible, you know. That was very helpful...And it was sort of an affirmation that things should get better”. This participant went on to say “And there was some sort of GBS web page. I used to get on that a lot, where you could talk to other people and ask questions and hear what other people’s experiences were. That was nice. That was helpful”.

### **Theme 5: Care Concepts**

The last theme that emerged from the data was titled care concepts. This theme reveals that impact that the lack of staff knowledge had on participants. In addition, this theme presents information related to the concept of personalized patient centered care and communication with caregivers. Finally, this theme illustrates the positive impact that accomplishing achievements has on participants. The care concepts theme resulted in four subthemes including (a) *staff knowledge and availability of information was “remarkably absent”*, (b) *personalized patient*

*centered care and interactions with staff, (c) communication with caregivers, and (d) impact of achievements.*

***Staff knowledge and availability of information was “remarkably absent”.***

The majority of participants discussed the knowledge level of physicians and clinical staff when responding to how they learned about Guillain-Barre Syndrome. The participants indicated that physicians and staff, for the most part, were not knowledgeable about this syndrome. In addition, participants expected that physicians and staff would have educated them more on the disorder. Some participants felt that the physician should know more than the nursing staff and should provide the education. A lack of provider and staff knowledge did cause an uncomfortable feeling for participants. One participant stated “You know, he’s my GP internist. He’d just get the big ol’ book out, and he said: We’ll just look for this together. He was never, you know, afraid of telling you that it was something I don’t know, but I know where I can look”. Another participant said “And so they [the nurses] didn’t know very much about Guillain-Barre’, and I remember when they gave [the IVIG] to me, they had some questions, you know, on how to – what, I guess the procedure was...the nurses that would always come in and not really understand how...to, um, administer it. So it would have been a little bit nicer, maybe, if they had reviewed what to do because they got a little bit confusing”. One participant stated “Well, I had a conversation with the lady that was in charge of the rehab center...And I told her, you know...you can’t believe when someone is in the state of mind that you are in when you’re in rehab. And people come in and are going to be your caregiver for that particular shift. And they know so little about your condition...I mean, if you’re going to have people dealing with people, they ought to have a little bit of knowledge. So, somebody that can really speak the

language and somebody who can relate and connect with the patient. I think it would be worthwhile...it would have certainly been a comfort to me”.

Physicians and staff not having a working knowledge of Guillain-Barre’ syndrome was not comforting to other participants as well. Another participant stated “I just wish that, um, that the people who were treating me had known more about it, You know, it’s not comforting when, you know, a nurse walks in and said: I didn’t know anything about it, so I had to Google it. You know, I didn’t find that comforting. And there were – there was more than one person that – that said they had never really heard of it”. Another participant stated “just the knowledge. You know? The lack of knowledge. The lack of information. The feeling, so desperately alone and, and...Nobody really giving me any comfort of along the lines of what might happen or might not happen. So...That I think, was remarkably absent”. Another participant shared similar feelings regarding staffs’ lack of knowledge. She stated “Doctors – you know, my biggest complaint about all of it is that they just that nobody knew very much about my illness. And that, you know, that made me not that confident? Whether it was – I didn’t really expect the nurses to know a lot. I expected the doctors to know a little more than they did”. She went on further to say “And I’d gotten to the point, you know, with even physical therapists and – if they haven’t seen somebody with Guillain-Barre, they don’t make an effort to do some research about it. And I’m not that interested in seeing them. You know? I don’t think they’re that helpful...they could know more about Guillain-Barre, and that would have made it better for me. And the ones that made an effort to do that, I particularly appreciated”.

Other participants also indicated that it appeared that if providers knew information about the illness, that they still didn’t have time to share the knowledge with the participant. One participant stated “I mean, the doctors – honestly, I understand that, you know, you’re doctors.

You're busy in a big hospital. But they don't have time to sit down with you and explain exactly everything that is going on. It's just: This is what you have. This is sort of how it works: And here's your prognosis".

Despite an apparent lack of knowledge and experience dealing with Guillain-Barre' patients, several participants commented that staff addressed their care needs that were related to the physical function impairments. One participant stated "my hunch is that they probably didn't have a lot of experience with it....they might not have been prepared...but as far as dealing with my disabilities, they were great. Even if they didn't understand what caused it themselves. But, you know, to help me do the necessities".

***Personalized patient centered care and interactions with staff.***

Several participants identified care concerns related to the provision of care that was not personalized to the patient experiencing Guillain-Barre' syndrome nor was the care patient centered. One participant discussed her experience with staff regarding the use of a bedpan versus the bedside commode. She revealed "I will take the bedside commode, but I will not do the bedpan. So that's really when they started telling me they were not going to move me. There were some [staff] during the day, and I knew who to ask for to help me do that during the day. But in the evening, they basically told me they were not going to help me. That I weighed too much". Another participant shared "The fact that my legs were so sensitive, and it felt like my legs were always either hot or cold; and that's not their fault, but there weren't enough nurses to keep ice packs and heating packs coming...So just limited staff...And that really saved me was when I get an ice pack, I felt like everything was going to be okay". Another participant also had an experience where limited staff impacted that personalized attention that he needed. He stated "after I got in rehab that was a totally different situation...the nursing staff was really

quite nice, quite professional, and very, you know, attentive; but the problem was they were stretched so thin. There were so few nurses on the floor, they would hire...these nurse's aides, and they couldn't speak English; so if you wanted anything you would have to communicate with them through sign language mostly...and so that was a problem...[and] they would come in and tell me to clean my teeth, and they would set the things down in front of me, and I couldn't move my arms...it was just awful". Another participant discussed rehabilitation concerns that occurred on the weekends. She stated "I think it's the system. The weekends. The long weekends of just waiting for the weekend to be over, and nothing really happening, in terms of rehab. Not being able to...being confined to the hospital, not being able to get out in fresh air at all was – made me crazy. You know, just wanted...to break out". Another participant reflected on her experience with rehabilitation and them not having an understanding of her limitations related to fatigue. She revealed "I remember one day they had me riding on a bicycle...[and] a physical therapists [should] not push, push, pushing somebody to the point of exhaustion. That's the only mistake – I wouldn't even say mistake. But you know what I mean. It's the only big thing...I just think it's set up for a different kind of rehab than what I needed".

Participants also provided positive feedback regarding the care that they received from staff and how the care was personalized to their needs. One participant, when discussing the kind of care that you need when you have GBS, described it as "It's, kind of, like your wife taking care of you. That level of attention. That level of care". This participant also had positive comments regarding the nursing care that he received at the second hospital where he was transferred. He stated "the nursing care was just absolutely unbelievably good. I mean, I've been in a number of – I mean, I've never been a patient in a hospital before, but I have been, you know, where I've visited numerous people; and I had never in my life seen anything even

remotely approached the level of care that I got at [this second hospital]. It was fantastic – and the same way with the doctors, the staff, they were unbelievable. I had the one doctor who was like – kind of, like my personal physician”. This participant indicated that this physician would check in on him every morning and every evening before leaving the hospital. Another participant stated “most of my care was ice packs and heating packs, pain medication; for the first day I needed help going to the restroom, but after that I wore diapers because I couldn’t get up. So it was...it was a lot of helping me be a human being still...and helping me do what I needed to do”. This participant went on further to say “It’s those little things the nurses do. And I’m sure they do it for everyone. But they bring you juice first thing when you wake up because when you’ve been their patient for three nights in a row now, and they know you like that. And...and when you need them, they’re there, as far as nurses go. Another participant described how a nursing aide provided assistance with activities of daily living by being creative and efficient. She stated “I still remember, when I am getting myself dressed, there was an aid...and she was the one that would help me get dressed. So she, you know would, I’d want to put my undies on and pull them up, and I’d want to put my pants on and pull them up. And she said...we’re going to do this a better way. We’re going to put those undies on and the pants on, then we’re going to pull up one time. And I thought: Great idea!”. Another participant also commented on the kind things that staff did. She said “She never seemed to be bothered by anything we asked. You know, I didn’t want to ask her to, like, give me a sponge bath. She was, like: Yeah, no problem. I’ll be right back. And then: Oh let me warm up the bottle for you so that the lotion is not so – so cold. You know, stuff like that, the small stuff, because she really enjoyed what she was doing”.

*Communication with caregivers.*

Participants experienced unsupportive communication with care providers. One participant had been to the Emergency Department several times seeking relief from the back pain that she was encountering. On a subsequent encounter to the emergency department “I had this doctor that, I swear if I could kick her, I would...you know, I’d been into the emergency rooms three or four times with my back pain, and she walks in and she – this is all she said to me was: Well, what do you expect me to do for you?...I never saw her again after that. That was the only exchange I had with her”. Another participant described communication with a nurse. She stated “An episode that happened we had one nurse – before I went into the ICU – and I actually asked her, I said: Have I done something to offend you? Are you mad at me? She was surly. And she didn’t really give me an answer. And I mentioned it later to another nurse. And she said: Well, you should report her to her supervisor. She’ll fire her immediately. I said: Well, why don’t you do it? [the other nurse said] It would be better coming from you. And I thought: Me, in bed, unable to do anything, I’m going to make a nurse mad at me? No way in hell I’m going to do that...I was not going to aggravate somebody who could – basically paranoid wise – come back and retaliate if she wished to. I was in a very vulnerable position”. One participant said “it seemed that everyone who came into my room [said] ‘You’re so lucky’...I heard that over and over again...And nobody explained what they meant by that. And I thought: That’s a cruelty joke to say that this [having GBS] is good fortune. You know?”. Another participant had a similar experience related to not finding value in being told that he would get better without any additional information provided. He stated “you know, you still don’t really know what the name of that truck was that hit you [and] they said: Oh don’t worry. You’ll get better. Well, you know, when you’re laying there, and you can’t even scratch your nose, and you have



this severe pain in your arms...it's hard to believe when somebody says – with no more information than that – that you're going to be better. I was sure they were blowing smoke at me. I really was". Yet another participant recalled an exchange with a physician. The physician had performed a nerve conduction test and he said "he did believe it was Guillain-Barre' syndrome" so the participant said "So what, you know, what's going to happen? And he said: Well, you know, you might get better. I mean he was very cavalier. I just looked at him as just being – just, kind of, trying to be cute with me...This guy was just like: Well, how long does it take nerves to heal? I don't know. Could be this. Could be that. You know? But just in not a very kind way, I don't think. I really resented that".

Other participants recall more positive and supportive communication that enhanced the participant experience. One participant revealed that the staff "were all so sweet and understanding about it; and they were all willing to say: I know it's scary, but come on. I'm going to help you". Another participant stated "I remember one nurse that I actually had conversations with. You know? Just everyday kind of conversations. It wasn't necessarily about GBS, but you know, just about everything in general. And I enjoyed that. Because I am a people person. I like to talk to people, so that part I remember". Another participant stated, "I have no complaints about their demeanor or the way they approached me".

### ***Impact of Achievements.***

Participants described key milestones and achievements that they recognized as being significant. Accomplishing these achievements were motivating to these participants. One participant stated "getting the diagnosis to me was the – was the hallelujah part for me...and being able to walk again was...great. Being able to go back to work. That was a really great achievement. The fact that, um, I could walk again -- on my own – was just amazing to me".

Another participant reflected on her major achievements and recalled “When I got out of ICU and stayed out for an entire day...my first step on a parallel bar. Being vertical for the first time...being out of the hospital...going home. And [then] my first unassisted step in outpatient therapy. It was such a big deal and I cried. I finally realized it was going to be okay...this little glimmer”. One participant stated, “learning how to swallow again. Being able to eat without being afraid that I was going to, you know, kill myself. After that...[the] first steps with your walker...[then] using the machine that [helped me] walk. That was a big day...[then after a few days]...taken 30 steps or something like that. So that was pretty momentous”. Another participant stated, “I like the successes when we have a goal in PT and I finally was able to stand unassisted. That was huge...So, succeeding in something was a feel good moment”.

### **Summary**

Data were collected from a demographic questionnaire and through qualitative interviews with 14 participants. These participants ranged in age from 19 to 79 and represented eight states most of which were southeastern states ( $n=10$ ).

Five themes with a total of 14 subthemes were identified during the data analysis process including (a) physical manifestations of GBS, (b) attitudes and emotions, (c) knowledge and awareness, (d) the value of peer contact, and (e) care concepts. Discussion of these findings follows in Chapter 5.

## **Chapter Five: Conclusions and Recommendations**

The purpose of this study was to gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome. Orem's self-care deficit theory of nursing informed the study. This chapter discusses the findings including the resulting themes and subthemes, as well as the implications for practice, healthcare provider education, healthcare policy, and research. Strengths and limitations also are reviewed.

The sample was comprised of 14 participants. The most recent studies indicate that the average age at onset of GBS is 40 years of age (Schub & Schiebel, 2014). Individuals in this study had an average age of 49.2 years (range 16 – 76) indicating that this sample of patients were older than the average patient diagnosed with GBS. In addition, there were more females than males in this study. Some studies found in the literature suggest that males and females are impacted nearly equally while other research indicates that males are affected at a higher rate of 3:2 (Schub & Schiebel, 2014). Onset of GBS for several participants followed an antecedent infection which is consistent with the literature. Of other interest, seven of the participants indicated that they had received an immunization in the six month period preceding their illness. Since the increase in the number of GBS cases in the mid 1970's related to the influenza vaccine, it has been determined that there is an extremely low chance of a link between immunization and the development of GBS. Schub and Schiebel (2014) report that the approximate risk of becoming ill with GBS after an immunization is extremely low (two cases per million). Participants were asked about the six months prior to becoming ill with GBS and were not asked about the exact date of the immunization.

This study sought to answer three research questions:

1. What are patients recalled experiences of care and caregiver interactions during an episode of moderate to severe Guillain-Barre' syndrome?

2. What do patients recall about the characteristics and environmental conditions of the clinical area(s) where they received care?
3. How do patients describe their change in knowledge of GBS over time from pre-diagnosis to current time?

Research questions were addressed through description of five themes and 14 subthemes. The five major themes were: (a) physical manifestations of Guillain-Barre' syndrome, (b) attitudes and emotions, (c) knowledge and awareness, (d) the value of peer contact, and (e) care concepts. Table 14 identifies the themes and associated subthemes. Appendix J provides a table that links research questions, interview guide questions, and resulting themes. The discussion includes information related to: (a) enhancing care of participants' physical and psychosocial issues (including both acute and rehabilitative care needs); (b) implications for education including nursing staff, interprofessional staff, and patient education; and (c) additional implications including peer counseling and organizational support resources.

## **Discussion**

Providing care to individuals with a rare disease presents numerous challenges for both the patient and the healthcare team. Nurses are particularly impacted because they have so much contact with the patient. This study accessed the participants' perspective so that care for GBS patients could be informed and enhanced. Further discussion is organized by each of the five themes.

### **Theme 1: Physical Manifestations of Guillain-Barre' Syndrome**

Theme 1 identifies how participants described the physical manifestations of Guillain-Barre' syndrome, how participants initially managed these symptoms, and the symptom and illness progression with particular attention to pain and fatigue. This theme addresses the first

research question which relates to the participants recalled experience of care and caregiver interactions. Descriptions of the symptoms are similar to what is found in the literature and demonstrates that the clinical presentation can be varied; however, similarities exist between participants' descriptions of their initial symptoms. Despite symptom onset and variation, participants utilized descriptors such as strange and odd sensations as well as peculiar feelings to describe how they felt when symptoms first became apparent before entry into the healthcare system. Participants described times when there was an increased sensitivity to touch. Atkinson et al. (2006) reported similar results. This increased sensitivity to touch often worsened pain-related symptoms. Participants further described tingling sensations throughout the body and commented that their feet felt like they were "asleep" and their legs cramped and felt weird. These symptoms impacted participants' ability to sleep.

Some described that their feet and legs would not work properly and they had to accommodate this by sliding their feet. Others also described the impact on their ability to ambulate and described the sensation as walking "six inches off the floor". Another indicated that that their legs and feet felt like heavy blocks. Symptoms, and their resulting impact on ambulation, did contribute to falls through various stages of the illness including prior to diagnosis at participant's place of employment, during hospitalization, and after discharge. Participants also commented on the impact of symptoms on their work responsibilities. One participant, employed in the healthcare field, commented on how strange her hands felt and this impacted her work. It was difficult for the individual to complete her work when trying to place her initials on all of the related documents that required her initials. Others experienced upper extremity complaints including inability to use hands and fingers to open containers. Another participant also described the sensation of bugs crawling all over her.

These descriptions are similar to what is found in previous research. Forsberg et al. (2008) described symptoms as strange sensations that included tingling, numbness, and increased sensitivity of touch. Participants in that study found their symptoms equally puzzling (Forsberg et al. 2008). Similar to participants in the current study, a participant described one of the sensations like the thickening of the soles of the feet. This was a similar symptom as described by participants in the current study. Like this study, the participants in Forsberg et al. (2008) study reported that these sensations impacted their ability to sleep. Additionally, individuals in the Forsberg et al. (2008) study also commented that their extremities, particularly the feet, felt as if they were asleep. As with prior research (Forsberg et al., 2008), this study also revealed that participants experienced balance issues including falling.

When participants experienced these strange and odd sensations, many of them attempted to explain away the symptoms by relating them to normal everyday activities and/or occurrences. Participants thought that perhaps these activities and/or occurrences could have precipitated the manifestation of symptoms. The activities and occurrences included minor illnesses and very active busy days. In addition, because symptoms appeared at or around the time of minor illness, participants approached these strange sensations without much caution. The reason for lack of caution was because participants related the symptoms to the commonly known minor illness, such as sinusitis or ear infection, that generally would not have long-term negative sequelae. One participant related her symptoms to possible effects of durable medical equipment. Forsberg et al. (2008) found similar results where participants either ignored their symptoms or related the symptoms to overworking or being tired. Unlike previous studies, there was not mention in the literature that participants related symptoms to a preceding illness or to any durable medical equipment.

Participants remarked on the pace as well as the level of progression of symptoms. All participants experienced a progression of symptoms eventually requiring healthcare that moved from these strange and odd sensations up to and including the need for mechanical ventilatory support. However, participants experienced differences in the pace of this progression. Some had symptoms that worsened over several days before requiring healthcare whereas some progressed over hours requiring emergent health care. One participant referenced this as “the downward spiral”. This was also identified in prior research. According to Forsberg et al. (2008), two themes were found regarding the onset of illness including (a) a slower more prolonged progressive onset versus and (b) a rapid frightening presentation. These findings of variable symptom progression were consistent with this current study.

Most participants experienced pain and fatigue throughout the course of the illness and into recovery. Some of the participants had pain prior to hospitalization while others experienced their pain after being hospitalized. Participants described their pain as significant using such descriptors as horrible and excruciating. Another descriptor that participants used was a burning sensation and one stated that it felt like her feet “were on fire”. Pain was so severe in some cases, that one participant, for example, returned to the emergency department. Prior to hospitalization, participants commented that the pain felt like muscles tearing. Many participants remarked on the need for polypharmacy to reduce the pain during and after hospitalization. Several participants described the pain as starting in the shoulders and radiating down the arms. Others described pain that started in back and radiated down legs. Participants remarked that the pain did impact their ability to achieve restful sleep. While some mentioned polypharmacy as a strategy to reduce pain, even this was not always effective. Participants described various strategies that were provided by staff to help them with their pain. Some remarked that hot

packs, ice packs, and arm massages were helpful; however, others could not be touched due to the resultant worsening of pain. Participants were familiar with the pain scale and one rated her pain as a nine on a 10 point scale. Regardless of pain management strategies and their effectiveness, pain was a significant complication for most participants. Understanding the unique individualized pain that GBS patients encounter is important for the healthcare team and impacts assessment and planning of care. Participants reported that there were times when nurses did not administer medications on a schedule that best ameliorated the pain.

Pain was also discussed in prior studies (Eisendrath et al., 1983, Forsberg et al., 2008) and revealed similar pain descriptions and severities. In the study by Eisendrath et al. (1983), a participant also described the pain as muscles being pulled on with chains. Many individuals in this study remarked on the need for improvement in pain management (Eisendrath et al., 1983). Generally, for those who encounter severe pain, polypharmacy will be required (Hughes et al., 2005). This study also reveals that multiple medications were required for pain and improvement in pain management strategies is needed.

Participants also described fatigue that resulted from their illness with Guillain-Barre' syndrome. Many used the terms like low energy, feeling weak, and exhausted when describing their fatigue. One participant referred to her fatigue as "the tired factor". Participants contributed their fatigue to several things including the effects of the illness itself, the resultant immobility, and overworking in rehabilitation, just to name a few. Many participants noted that the fatigue was progressive and remarked that it continued into recovery. Participants noted that their muscles just couldn't perform and that fatigue impacted functional abilities, like eating. Fatigue in GBS has been reported by others (Gregory, 2003). Fatigue is a persistent issue in individuals and doesn't seem to be related to their age, the length of time that they were ill with



GBS, or the illness' initial severity level (Hughes et al., 2005). Participants reported that there were times when members of the healthcare team did not identify that fatigue was an issue for the participant. Additionally, participants indicated that the healthcare team did not recognize the need to alter the plan of care related to fatigue management in GBS patients.

## **Theme 2: Attitudes and Emotions**

Theme 2 reveals the attitudes and emotions that participants experienced during their course of illness. This theme addresses all three research questions related to the participants recalled experience of care and caregiver interactions, environmental conditions, and knowledge level. Care and caregiving interactions influenced their attitudes and emotions. Some interactions positively contributed to participants emotions while other did not. Participants also remarked on the impact of environmental conditions and knowledge, or lack of, on their attitudes and emotions.

Participants encountered a wide range of emotions as a result of being diagnosed with Guillain-Barre' and the subsequent care that was required. Participants commented that the emotions were strong and utilized the following terms to describe the array of emotions: agitation, anger, anxiety, bewilderment, confusion, curiosity, demeaning, determined, dismay, embarrassing, fear, frustration, guilt, hopeful, mad, scared, terrifying, traumatizing, and worry. Participants described being agitated about how staff communicated with them about what they were not allowed to do. Participants described being angry at why this (having Guillain-Barre' syndrome) was happening to them. In addition to anger, several other emotions such as confusion, were experienced related to why GBS was happening. One participant related how she responded to the anger like that of a temper tantrum. She commented on how she would just

yell out asking “why was this happening?”. Participants also expressed anger over care concerns.

Many participants discussed experiencing fear which was multifactorial. Participants encountered fear as a result of not knowing what Guillain-Barre’ syndrome was and what impact it was going to have on their lives; they were essentially fearful of the unknown. A source of fear for participants was related to their questioning of future wage earning capabilities, as well as impact on other life activities, in the event that they had long term limitations in function related to the illness. Participants were fearful and worried about the future. One participant seemed to want to justify her emotions. She discussed that her questions about GBS and the impact that it was going to have on her were “legitimate worries” and cause for being scared.

Participants described other feelings including guilt and embarrassment. Participants felt guilt over the amount of pain medication they required. Participants also expressed guilt when thinking about the effect that their illness was having on family member’s well-being.

Other participants described being embarrassed by having to have certain care, particularly bathing and the provision of perineal care after incontinence, that were provided. Participants indicated that this experience was demeaning and traumatizing. Concepts of patient-centered care would support developing individualized plans to support both patient independence and privacy.

The emotions that were encountered in this study have been described in part previously. Forsberg et al. (2008) discussed the concept of fear. There are many similarities between the participants’ descriptions of fear in this study as compared to previous research. Fear is experienced by individuals for many reasons including: lack of knowledge about the illness,

pain, communication issues related to paralysis or ventilation, and becoming dependent, just to name a few (Atkinson et al., 2006).

Participants did describe how healthcare team members provided information about their illness and how this made them feel. Essentially, providers advised the participant that recovery was most likely but didn't provide supporting information regarding how this improvement would happen or the anticipated timeframe. Participants felt like providers sharing that they would improve, but not substantiating this with additional information, negatively impacted their attitudes and emotions.

Emotional challenges also were apparent secondary to a loss of independence. All severities of Guillain-Barre' syndrome impact an individual's physical functioning. Naturally, the more severe the case of GBS, the more physical functioning is impaired. Participants described a need for increased control and independence. Individuals desired the need to control their bodies and/or their environment and were excited and motivated when this was possible.

According to Weiss et al. (2002), individuals with GBS express emotional distress. This distress manifests itself in different ways. Participants in the previous research experienced anxiety, stress, depression, hopelessness, and insecurities (Weiss et al, 2002). Participants in this study indicated the value of positive staff interaction in impacting their outlook.

However, many participants in this study also expressed positive feelings such as determination, elation, and hopefulness. The feeling of being determined and being hopeful was experienced by participants who had started to see improvements in the functional abilities or those that began to accomplish goals and achieve milestones. Many participants were excited to be leaving the hospital and one described it as a feeling of "elation". More than one participant indicated that GBS had changed their lives making them appreciate the small things in life. One

even stated that GBS had “been a good thing for” her. The impact of Guillain-Barre’ syndrome is dramatic and because of the pace of new onset functional impairment, individuals will experience a flood of emotions. The positive feelings experienced by patients with GBS have not been fully presented in the literature.

Considering the vast emotional component of this illness, participants described coping strategies. Many participants used the power of a positive attitude to manage their emotions. Participants recognized that maintaining a positive attitude helped them maneuver through the emotional challenges of the illness. Maintaining a positive attitude is an important and helpful coping strategy. A positive attitude allowed participants to have hope and believe that the next day would be better. Participants shared that a positive attitude allowed them to see that there was “light at the end of the tunnel” and that despite having Guillain-Barre’ syndrome and any of the potential long-term functional impairment, “a good life” was possible. The participants who described having positive attitudes did this independently and there was no mention of mental health professionals being part of the care received.

Despite the significant emotional and physical burden of moderate to severe GBS, several participants expressed a concern for their spouses or parents while they were hospitalized. This concern was in relation to the comfort of the family member in the hospital room as well as where family was receiving support since the patient was not able to provide it. In addition to participants expressing concern for their loved ones, many of them also expressed appreciation for their family’s presence while they were hospitalized. For many, GBS and hospitalization resulted in families being close by and care came from family as well. There was also an appreciation for the family members serving in an advocacy role for the participant. This was a

unique result of this study. Previous research did not discuss the participants' concerns for their support systems.

The psychosocial impact of this illness on the patient and the family as identified in this was significant yet little information is available about how to effectively address the psychosocial aspects of Guillain-Barre' syndrome. Care strategies outlined in the literature as summarized in Table 7 are generally related to the physical care requirements of the immobilized or paralyzed patient. More direction is needed on how nursing staff can effectively manage the specific psychosocial needs of the GBS patient.

### **Theme 3: Knowledge and Awareness**

This theme specifically relates to the third research question about the participants' initial knowledge level of GBS and how this knowledge changed. No participant had knowledge of Guillain-Barre' syndrome prior to his/her illness. Most indicated that they had never heard of the disorder. A couple of participants indicated that they may have heard of GBS in relationship to influenza vaccination; however, they knew nothing about it. The lack of knowledge resulted in some participants minimizing the potential impacts of the illness, where others were scared by it. Prior studies have also highlighted that participants experience a knowledge deficit regarding GBS (Eisendrath et al., 1983).

Most participants desired more knowledge about GBS. Because of this, participants and their families used a variety of strategies to retrieve information including: asking questions of physicians, accessing educational resources through the GBS/CIDP Foundation International, contact with the Center for Disease Control, books written by individuals who had previously encountered GBS, and the Internet. The Internet was the most commonly mentioned strategy for obtaining information related to this illness. Participants were not satisfied with the amount of

information and education that was shared with them from physicians and staff about their illness. Participants' desire for additional information has been documented. In this and other studies, participants utilized the Internet, medical books, and information from physicians to increase their knowledge level (Forsberg et al., 2008; Gregory, 2003). There was no discussion in the prior research related to lack of education from physicians and hospital staff.

When participants received information, most commented on the value of this increased knowledge regarding GBS and their outlook for the future. Many were encouraged that significant improvement, up to and including full recovery, was probable. There were exceptions with some participants expressing concern about the information that was available on the Internet, such as on blogs, and found that the information was generally negative rather than being a more balanced message regarding what the future may hold.

One participant mentioned concern related to the information that she received when she was diagnosed. This particular participant encountered minimal symptoms in the early stages of her illness. She was provided a brochure, by the neurologist, regarding GBS. While she appreciated the information, there was a lack of discussion between the neurologist and the participant about the contents of the brochure. Considering her initial minor symptoms, she was scared to learn that total paralysis, and other limitations, was possible. In addition to the brochure, she desired communication with the physician concerning the information provided. This also was mentioned in prior research. When participants, in earlier study, were provided with a comprehensive discussion of potential residual functional impairments, they were doubtful that they would improve (Forsberg et al., 2008). Only a few participants mentioned having knowledge of, and accessing all of the available resources at, the GBS/CIDP Foundation

International. This should be an area of focus for the Foundation and healthcare providers who care for these patients.

#### **Theme 4: The Value of Peer Contact**

Many participants recognized and discussed the importance and value of having access to communication with individuals who have previously had GBS. A primary outcome of these conversations reported by participants was creation of hope about recovery and the future. Having access to peer counselors was noted to be extremely important for GBS participants, especially considering its classification as a rare disorder. Participants expressed interest in learning from peer counselors through their stories of the path to recovery as well as the strategies that they utilized to help gain improvements. Participants felt that hearing information from an individual who had encountered GBS would be perceived differently than when compared to communication coming from hospital staff. Some participants indicated that they had or would be willing to volunteer as peer counselors. One participant also mentioned that they had utilized an online discussion forum with peer counselors, that was available through the GBS/CIDP Foundation International website. The value of peer communication was described previously (Gregory, 2003). In addition, another valuable resource for individuals was GBS support groups (Gregory, 2003). Support groups were not mentioned in the current study. According to Gregory (2003), the technique used to communicate with a peer counselor, such as in-person meetings, phone contact, or other electronic mechanisms, was not as important as the connection itself.

#### **Theme 5: Care Concepts**

Participants were queried regarding their recollection of any memorable care moments. Most of the participants identified both positive and negative care encounters. The theme care

concepts involves the positive impacts of patient-centered care, good communication, and the accomplishment of milestones. It also involves the impact of the lack of staff knowledge.

The first component of this theme relates to the issue of staff's lack of knowledge and the scarcity of information that was available to participants. Of those participants who commented on physician and staff knowledge of GBS, all indicated that physicians (with the exception of neurologists and some of the emergency department physicians that were encountered) and staff were not knowledgeable about this illness. This lack of knowledge caused participants to have an uncomfortable feeling and impacted their level of confidence in their care providers for example related to nursing procedures such as administration of intravenous immunoglobulin (IVIG). Other participants mentioned that multiple caregivers, including physicians and interprofessional team members, indicated that they knew nothing about Guillain-Barre syndrome. Another participant mentioned that a caregiver proclaimed that they knew nothing about the illness and had "Googled it". The participant commented that it was not comforting to know that the nurse had to "Google" the condition in order to care for her. Many participants reflected on the lack of patient-centered personalized care providing examples of care related concerns. Participants provided negative examples such as limited staffing, week-end issues, and care that lacked sensitivity to patient needs.

In addition to the issues that were identified as concerns, participants commented on the positive care moments as well. One participant related the kind of care he needed, because of his total dependence, to that that his wife would provide. The care required of a totally dependent patient is an intimate experience. Participants provided compliments to caregivers and used words like unbelievably good and fantastic to describe the care. Participants also commented that staff helped them do what they needed to do which was helping them basically being human



still. Participants were reflecting on the essentials that staff provided such as assistance with feeding, providing care after incontinence, and ensuring a secure airway. Several participants also commented on and appreciated that staff were creative when caring for them including helping with assistive devices to make tasks easier.

Communication between participants and caregivers was also important with participants describing both positive and negative communication encounters, ranging from verbal encounters with emergency room physicians to exchanges with nursing staff. Of the five individuals who required mechanical ventilation, all commented on communication. Participants indicated that they utilized communication boards, lip-reading, and specialty nurse call lights in order to communicate with staff. Most of the ventilated participants indicated that communication was adequate but was a challenge. One ventilated patient's daughter created an effective communication board that the participant found to be very helpful in communicating with staff. Current literature is replete in discussing the value of effective communication for all patients. It would seem much more so, with patients with rare disorders such as GBS.

Participants described how achieving key milestones resulted in motivation to keep working to improve. Achieving key milestones and making improvements ranged in scope based on each individual and included: getting the diagnosis, staying out of intensive care for 24 hours, being able to breathe without the ventilator, learning how to swallow again, being able to take a step on the parallel bars, being vertical for the first time, being able to walk, being out of the hospital, the first unassisted step in outpatient therapy, and being able to go back to work. Achieving these successes was described as momentous and this made participants feel good.

### **Implications for Practice and Education**

The following discussion includes information related to enhancing care of participants' physical and psychosocial issues, including both acute and rehabilitative care needs; implications for education including nursing staff, interprofessional staff, and patient education; and additional implications including peer counseling and organizational support resources.

Provision of nursing care for the Guillain-Barre' syndrome patient population is challenging. Individuals who experience a diagnosis of moderate to severe Guillain-Barre syndrome will require significant support from nurses as well as other members of the interdisciplinary care team during hospitalization. The need for nursing care becomes apparent because individuals with GBS will encounter physical symptoms and functional impairments that prevent them from performing self-care activities. Orem's Self-care Deficit Theory supports this idea. Nursing care is needed when an individual cannot perform self-care activities to meet their own needs (Hudson & Macdonald, 2010). While participants generally share positive feedback regarding routine nursing care, the lack of the nursing team's knowledge negatively impacts the GBS patient's overall care experience. Orem indicates that one of the responsibilities of the nurse is to use supportive-educative systems to assist the patient in obtaining requisite knowledge (Hudson & Macdonald, 2010). Because of the rarity of this illness, and nurses' limited exposure to this patient population on a regular basis, the use of the supportive-educative system for these individuals impacted with GBS was not evident in this study. The nursing team should educate themselves on the symptoms to assess for in early GBS as well as the special needs of GBS patients to enhance the overall level of nursing care provided.

There are nearly 7000 recognized rare diseases in the United States (Griggs et al., 2009). It is not reasonable to expect nurses to have a comprehensive working knowledge of all of these illnesses. However, nursing team members need to know how to access resources regarding rare illnesses to improve their own as well as their patient's knowledge regarding their illness when a patient with a rare disease presents. Nurses and other healthcare team members also need to learn more about how to communicate balanced information with GBS patients so that fear and anxiety can be mitigated.

This study supports previous research demonstrating that GBS is an emotionally impactful illness. A wide range of emotions are experienced and psychosocial support is necessary. It is important for nurses to assess, recognize, and discuss their patients' emotional symptoms with the individual themselves, their physician, and other healthcare team members to ensure that these psychosocial needs are part of the patient's care plan. Mental health clinicians can be utilized as a resource in this patient population to assist with the many emotions that the patient will experience. In addition, it is important for patients to be linked to the GBS/CIDP Foundation so that a peer counselor can be identified if desired. Many of the participants in this current study identified the importance of this strategy. Being able to connect with an individual who has previously had GBS and recovered was particularly important for these patients.

Pain management is another critical element in the care of the GBS population. Twelve participants described having pain that is consistent with prior studies which reports that 89% of GBS patients experience pain. In many cases, patient's pain levels were not well controlled. Nurses need to have a working knowledge of pain management concepts in order to make recommendations to physicians on the patient's behalf. Nurses also can use their assessment skills to identify what strategies work for the patient. This is important as GBS patients

experience pain in different ways and pharmacologic and non-pharmacologic strategies work differently in different individuals. Some strategies, like massage, that are beneficial for some individuals cause excruciating pain for others. Considering that GBS patients experience symptoms variably, nurses will need to use assessment and planning strategies to develop a unique personalized patient centered plan of care.

There are a host of other care strategies that are important for physicians and nurses to order and implement for the GBS patient: intravenous immunoglobulin or plasmapheresis based on certain clinical information; airway management, if applicable; working with rehabilitation on mobility; monitoring for signs and symptoms of infection, evaluating and protecting skin integrity, and working with dietitians regarding nutrition (Bowyer & Glover, 2010). The plan of care for GBS patients will be complex and require multidisciplinary collaboration and communication in order to provide the patient with the best care experience possible.

Patients with moderate to severe Guillain-Barre' will need rehabilitation services (Hughes et al., 2005). Despite this need, long-term outcome studies that are related to rehab services with GBS participants do not exist nor do studies comparing different rehab models (Hughes et al., 2005).

As with other neuromuscular illnesses, overworking a particular motor unit in a GBS patient can cause fatigue that can negatively impact recovery (Hughes et al., 2005). Participants in this study commented on being overworked in rehab therapy. Participants also described feeling that the model of rehab that they were exposed to was more for orthopedic illnesses versus neuromuscular ones. Additional research is needed in the area of neuromuscular rehab plans.

This work has started in Brazil where new rehab models for neurological patients are being studied (Jorge et al., 2015).

While it would not be reasonable to expect healthcare academic programs to expose students to the nearly 7,000 rare diseases, students ought to be introduced to resources regarding rare diseases and how to access these resources in the future. This would allow for practitioners to search for and obtain information about rare diseases in the event that they were called to provide care to one of the 30 million Americans who currently have a rare condition (Rubinstein et al., 2010).

Healthcare system education departments also need to investigate how they can support the bedside caregiver when a patient with a rare diagnosis is admitted. With the increase use of point of care technologies, an electronic strategy is feasible. The creation of on-demand video educational sessions (or podcasts) for both caregivers and patients would be beneficial. These on-demand educational videos could educate healthcare providers as to the standard of care for rare disorders. This would also meet The Joint Commission's requirement that healthcare staff should have competencies for low volume high risk illnesses and treatments that they may encounter.

### **Implications for Healthcare Policy**

There is a need for a rare disease patient registry. The idea of an international registry for patients with rare diseases was discussed at a 2010 meeting sponsored by the Office of Rare Diseases Research (Rubinstein et al., 2010). Numerous challenges were identified with a registry of this magnitude; however, extreme excitement regarding the impact that this could have was expressed (Rubinstein et al., 2010). It seems if there was one database that rare disease information could be housed, and with a patient's ability to opt-in with informed consent, that this would be a good way to potentially connect people to create a peer counseling network.

Additionally, it would also be advantageous to both the lay public and the healthcare professional team if there was a standard nomenclature and organizational structure when searching for rare disease information. For example, in some places where individuals would search the Internet, you would find Guillain-Barre' syndrome listed as GBS, GBS/CIDP, Guillain-Barre' syndrome. In most cases, items are listed on the webpages in alphabetical order making finding these illnesses a challenge if they are not named and organized the same way for each illness. Having a standardized nomenclature and organizational methodology would allow for ease in searching and locating information related to these rare diseases. With the time challenges that the healthcare team of today faces, efficiency in locating evidence-based standards of care is essential. This standard approach would also assist the lay public in more quickly identifying information that may be helpful.

### **Implications for Research**

There are limited previous studies regarding the experiences of individuals' who have required hospitalization, secondary to having GBS. More research is needed with additional participants. Additional research studies utilizing mixed methods designs where participants could be further segregated into more homogenous cohorts such as age categories, GBS disability scores, year of onset to determine if this impacts recall, issues encountered during the recovery phase, impact of residual deficits could provide greater detail regarding certain segments of the GBS population. Future research should also explore the relationship between GBS related pain and fatigue and how these symptoms impact the individual's ability to obtain adequate periods of restful sleep. More research on both the emotional and physical impact of GBS and how best to support patients is indicated. Additional research also is needed with family members of GBS patients in order to understand better the impact that this illness has on

them individually but also on the family unit. Research is needed with healthcare professionals who have had the opportunity to care for GBS patients to understand their challenges with managing this patient population. Additional research with healthcare professionals who have not cared for an individual with a rare disease and what strategies would they employ to care for an individual who presented with a rare disease could also prove useful if such a population could be identified.

Individuals who expressed an interest in participating in this study, but were advised that enough participants had already been recruited, were queried about interest in future studies. Of the 75 additional individuals, many responded affirmatively that they would have interest in being contacted in the future for other GBS related research studies. This researcher plans to continue a program of research in GBS.

### **Strengths and Limitations of the Study**

This study has several strengths including the qualitative approach; the maximum variation in several demographic indicators for the participants; one researcher collected all of the data; and the use of two interview strategies, in-person face-to-face and electronic face-to-face. While there were two strategies of interviewing, all were face-to-face. This is a strength for this study because of the researcher's ability to visually observe the participants reaction and response to questions. The qualitative descriptive design allowed for the study of a human problem (a diagnosis with GBS and subsequent hospitalization) from the participant's view (Creswell, 2009). This design provided for a rich description of the participants' experience with GBS using their own words (Neergaard et al., 2009). The sample for this study was purposively selected and maximum variation of participants was observed. Variation existed in terms of participant age at time of illness onset (age range 16 to 76), geographic location with participants

residing in eight different states, days hospitalized (less than 10 to greater than 365 days), and time from illness onset to time of interview (six participants' illness occurred within the last five years, four between 2000 – 2010, and one participant in the 1970s). Another study strength was the primary researcher performed all of the interviews that allowed for consistency in the interviewing process and with data collection.

Study limitations include the number of women in the sample, racial demographic, geographic locale, the time between GBS diagnosis and interview, and the fact that participants self-selected to participate in this study. In this study, there were 10 female participants and four male participants. Past research demonstrated that GBS affected men and women nearly equally; however, the most recent research indicates a 3:2 ratio of men to women in terms of disease prevalence (Schub & Schiebel, 2014). Another limitation for this study was that 12 of the participants identified as Caucasian or White. While considered a strength because of the number of states represented (eight), this is also a limitation for this study. Ten of the participants were from states located in the southeastern part of the United States. This could be considered a limitation related to transferability of study results to individuals in other parts of the country. Another limitation relates to the time between GBS diagnosis and participation in this research study. Appendix K includes a table that demonstrates the year that the participant was diagnosed with GBS compared to date of research interview. Participants for this study self-selected to participate. Some of the participants who participated in the study are or have been involved and serving as liaisons for the Guillain-Barre' syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International. Individuals who self-selected may or may not have a similar characteristics to those who did not volunteer to participate.



## **Conclusion**

Guillain-Barre' syndrome (GBS) is a rare disease that impacts the peripheral nervous system. GBS is now the leading cause of flaccid paralysis in the United States (Chalela, 2001; Napgal et al., 1999). GBS is a term that is used to describe several variants of this illness. Moderate to severe cases of GBS can result in significant functional impairment in patients, sometimes temporary and other times permanent (Frenzen, 2008). Patients encountering a moderate to severe case of GBS will require nursing care, whether wholly compensatory, partly compensatory, and/or supportive and educative. GBS patients are unlike other patients (DeCort, 2011). GBS causes considerable mortality and morbidity (Hartung et al., 2001). This neuromuscular illness is a challenge to manage for the healthcare team, especially nurses (Haldeman & Zulkosky, 2005; Murray, 1993; Sulton, 2002; Walsh, 2006). Patients have described that nursing care for GBS patients has been inconsistent (DeCort, 2011). In part, this has been because nurses are not aware of the special needs of the GBS patient which results in unnecessary discomfort and stress (DeCort, 2011). According to Murray (2010), Guillain-Barre' syndrome is simply not well understood by nurses.

The results for this study lead to the development of five themes and 14 subthemes. The first theme was physical manifestations of Guillain-Barre' syndrome which includes four subthemes: "a strange sensation", a rationalizing of symptoms, "the downward spiral", and pain and fatigue. The second theme was attitudes and emotions and includes four subthemes: the "emotional rollercoaster", "attitude is everything", seeking independence, and concerns for others. The third theme was knowledge and awareness and includes two subthemes: "no earthly idea what GBS was", and a desire for more knowledge. The fourth theme was the value of peer contact. The fifth theme was related to care concepts and includes four subthemes: staff

knowledge and available information was “remarkably absent”, personalized patient centered care, communication with caregivers, and impact of achievements. These themes and subthemes would suggest that healthcare team members, including nurses, do not have a complete understanding of the special needs of Guillain-Barre’ syndrome patients. Additional work and research is needed to enhance the patient’s experience with moderate to severe Guillain-Barre’ syndrome.

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## **Appendix A**

### **Guillain-Barre' Syndrome Treatment Options**

#### **Treatment utilizing Corticosteroids**

Researchers have studied the use of corticosteroids in the treatment of Guillain-Barre' syndrome. The use of corticosteroids preceded the use of the other treatment options (Atkinson et al., 2006). Despite the early use of corticosteroid therapy, there was not an absolute understanding of corticosteroid effect on the pathophysiology of Guillain-Barre' syndrome (Atkinson et al., 2006). The rationale for the use of anti-inflammatory agents in Guillain-Barre' was secondary to the inflammation of the nerves that was associated with the autoimmune component of this disorder (NORD Hughes, 2011; Atkinson et al., 2006). Additional support for corticosteroid use included evidence that corticosteroid therapy had been shown to be advantageous in the management of other demyelinating illnesses with presentations similar to Guillain-Barre' syndrome (Atkinson et al., 2006).

The route of corticosteroid therapy, as well as its combined use with others therapies, has been studied in patients affected by Guillain-Barre' syndrome (Atkinson et al., 2006). Clinical studies have reviewed the use of corticosteroids that were ordered and administered in the following ways: (1) 500mg of methylprednisolone intravenously for five days daily versus a placebo; (2) 40mg of prednisolone orally administered daily for 14 days versus a placebo; (3) prednisone and plasma exchange concurrently versus supportive care only; and (4) intravenous methylprednisolone and IVIg concurrently versus IVIg alone (Atkinson et al., 2006). Atkinson et al. (2006) presented the results of a meta-analysis that was performed which reviewed the use of corticosteroids in the medical management of Guillain-Barre' syndrome. The clinical studies outlined and the meta-analysis revealed that corticosteroid use in the Guillain-Barre' syndrome

patient as first-line primary therapy was not beneficial (Atkinson et al., 2006; Khan, 2004). The lack of efficacy of corticosteroid use was also discussed by other authors as well (Dimachkie & Barohn, 2013; Galloway, 2006; Meena et al., 2011; National Organization for Rare Disorders, 2011; Pritchard, 2008; Rajabally & Uncini, 2012).

### **Treatment utilizing Cerebrospinal Fluid Filtration**

Another therapy that has been minimally utilized in the treatment of Guillain-Barre' syndrome is cerebrospinal fluid filtration. Cerebrospinal fluid filtration is considered a potentially new therapy for this syndrome but additional study is warranted (Atkinson et al., 2006). Cerebrospinal fluid filtration originated in Germany in the later part of the 1980s and has been utilized to treat bacterial meningitis and other autoimmune diseases (Tzabar & White, 1999). The purpose of filtering the cerebrospinal fluid is to eliminate any substances that could possibly lead to Guillain-Barre' syndrome (Tzabar & White, 1999). Since the exact cause of Guillain-Barre' syndrome is unknown, the filtration process is not focused on the removal of any one substance (Tzabar & White, 1999). Filters are "designed to eliminate cells, bacteria, endotoxins, immunoglobulins, and inflammatory mediators" (Atkinson et al., 2006, p. 259). Electron microscopy results from filtered cerebrospinal fluid samples found "cells, cellular debris, immune complexes and other proteins" on the filters (Tzabar & White, 1999, p. 916).

The cerebrospinal fluid filtration process requires the placement of an epidural catheter into the subarachnoid space (Tzabar & White, 1999). Once the catheter is in proper position, the catheter is connected to a cerebrospinal filtration system. The cerebrospinal filtration system includes a 0.2mm polyester matrix filter, a bypass equipped with a one-way valve, a 50ml syringe, and a bidirectional syringe pump (Tzabar & White, 1999). In the cerebrospinal fluid filtration process, 20 to 50 ml of cerebrospinal fluid is removed at a rate of 1.5 to 2.0 ml/min

through the bypass valve by way of the syringe pump (Tzabar & White, 1999). The cerebrospinal fluid is then re-instilled via the syringe pump at a rate of 2.0 to 4.0 ml/min (Tzabar & White, 1999). Tzabar and White (1999) reveal that when the cerebrospinal fluid is returned to the subarachnoid space it passes through the filter. Cerebrospinal fluid is filtered ten times daily for five days and then repeated for three weeks (Tzabar & White, 1999). In one study, 37 randomized Guillain-Barre' syndrome patients received either cerebrospinal fluid filtration or plasma exchange (Wollinsky et al., 2001). Results of the study revealed that the cerebrospinal fluid filtration therapy was as effective as plasma exchange (Atkinson et al., 2006). Because of the number of patients in this study, Hughes, Pritchard, and Hadden (2013) suggest an inability to "confirm or refute benefit or harm in acute" Guillain-Barre' syndrome patients (p. 2). Additional study utilizing this treatment is needed to evaluate efficacy in a larger cohort of patients.

### **Treatment utilizing Immunotherapy**

Because of the strong evidence supporting the autoimmune component of Guillain-Barre' syndrome, treatment is generally focused on immunotherapy. There are two commonly utilized immunotherapy medical treatments: (1) plasmapheresis (or plasma exchange, PE) and (2) the administration of intravenous immunoglobulin G (IVIg). Both plasmapheresis and intravenous immunoglobulin administration have been shown to be effective in the treatment of Guillain-Barre' syndrome patients (Asbury, 2000; Burns, 2008).

#### **Plasmapheresis.**

Plasmapheresis was the first effective treatment for Guillain-Barre' syndrome patients to be identified in two randomized controlled trials in the mid-1980s (Dimachkie & Barohn, 2013). One of the studies was performed in North America in 1985 and was known as the Guillain-

Barre' Syndrome Study Group (n=245) and the other was performed in 1987 and was a French study known as the French Cooperative Group (n=220) (Dimachkie & Barohn, 2013). In these studies, plasma exchange was performed within two weeks of initial symptoms (Dimachkie & Barohn, 2013). Reductions in time to wean from mechanical ventilatory support and to walk unassisted were shown to be statistically significant in the treatment group as compared to the control group (Dimachkie & Barohn, 2013). In addition, the number of patients requiring assisted ventilation in the treatment group was less than in the control group and there was a reduction in the amount of time needed to see motor recovery comparing the treatment group with the control group (Dimachkie & Barohn, 2013).

Plasmapheresis is the process of separating plasma from whole blood using centrifugation or filtration and removing substances that can contribute to an illness, in this case Guillain-Barre' syndrome (Atkinson et al., 2006). These substances can include "autoantibodies, immune complexes, complement, cytokines, and other nonspecific inflammatory mediators" (Dimachkie & Barohn, 2013, p. 500). Once the substances are removed from the plasma, the plasma is administered back to the patient. In some cases, the patient's plasma is not returned and is rather replaced with normal plasma or albumin (Atkinson et al., 2006). The plasma exchange treatment volume is well established (Dimachkie & Barohn, 2013). Fifty milligrams per kilogram (50 mL/kg) of plasma is generally administered, either daily or every other day, for a five to ten day period yielding a total volume of 250 mL/kg (Dimachkie & Barohn, 2013). Dimachkie and Barohn (2013) reveal that plasma exchange volumes that exceed the normally prescribed amount do not result in improved outcomes. The French Cooperative Group study revealed that patients admitted with a mild case of Guillain-Barre' syndrome should receive two plasma exchange regimens and those admitted with a moderate case of Guillain-Barre' syndrome



should receive four plasma exchange regimens (Dimachkie & Barohn, 2013). The French Cooperative Group study also revealed that patients admitted with a severe case of Guillain-Barre' syndrome did not benefit from more than four plasma exchange regimens (Dimachkie & Barohn, 2013). Plasma exchange is performed in specialized units, requires a double-lumen catheter, can be accompanied by numerous potential complications, and requires close monitoring of vital signs and laboratory data (Dimachkie & Barohn, 2013). These circumstances should be considered and discussed with the patient prior to initiation of therapy.

### **Intravenous Immunoglobulin.**

The efficacy of intravenous immunoglobulin was established in 1992 in a large study, the Dutch Guillain-Barre' Study Group (n=147), and subsequently in the 1997 Plasma Exchange and Sandoglobulin Guillain-Barre' Syndrome Trial Group (Dimachkie & Barohn, 2013). The Dutch study compared the benefits of plasma exchange versus intravenous immunoglobulin (Dimachkie & Barohn, 2013). The Sandoglobulin Guillain-Barre' Syndrome Trial evaluated plasmapheresis alone, intravenous immunoglobulin alone, and plasma exchange followed by intravenous immunoglobulin (Dimachkie & Barohn, 2013). The outcomes from both of these studies revealed that patients treated with intravenous immunoglobulin had similar positive benefits as those patients treated with plasmapheresis (Dimachkie & Barohn, 2013). There was no statistically significant benefit in terms of improved patient outcomes when both therapies were used together (Dimachkie & Barohn, 2013).

The normal total dosing for intravenous immunoglobulin is generally 2g/kg administered over two to five days (Dimachkie & Barohn, 2013). Patients should be monitored closely to observe for any potential reactions or side effects. Side effects can include mild, moderate, and severe reactions. Mild reactions are rare and can include: "headache, nausea, chills, myalgia,

chest discomfort, [and] back pain” (Dimachkie & Barohn, 2013, p. 502). Moderate reactions can include: chemical meningitis, neutropenia, desquamation of palms, trunk, and soles of feet (Dimachkie & Barohn, 2013). Severe reactions are also rare and can include: “anaphylaxis, stroke, myocardial infarction, [and] pulmonary emboli caused by hyperviscosity syndrome” (Dimachkie & Barohn, 2013, p. 502). Dimachkie & Barohn (2013) reveal that infusions should start slowly at a rate of 25 to 50 mL/hr and then increasing the rate by 50mL/hr every 15 to 20 minutes until the rate has reached 150 to 200 mL/hr. Starting infusions slowly and then slowly increasing the volume administered per hour decreases the potential for side effects and enhances patient tolerance of the treatment (Dimachkie & Barohn, 2013). Table A1 summarizes treatment options and associated efficacies of these treatments.

### **Other Potential Treatments**

Hughes et al. (2013) performed an analysis of all available randomized controlled trials to review medical interventions other than corticosteroid therapy, plasmapheresis, and intravenous immunoglobulin. The initial analysis was performed in 2011 and updated in 2013. The analysis resulted in four studies, all of which were of low quality, outlining medical therapies including: (1) interferon beta-1a (used in treatment of multiple sclerosis) versus placebo (n=13), (2) brain-derived neurotrophic factor (a nerve growth factor) versus placebo (n=10), (3) cerebrospinal fluid filtration versus plasma exchange (n=37) (presented in previous section), and (4) tripterygium polyglycoside, a Chinese herbal medicine, versus corticosteroid therapy (n=20) (Hughes et al., 2013). Because of the number of subjects in these studies, drawing conclusions regarding “benefit or harm” of these therapies could not be confirmed or refuted (Hughes et al., 2013, p. 2). Additional treatment options are needed in the acute Guillain-Barre’ syndrome patient population.

Table A1

*Guillain-Barre' Syndrome Treatment Options and Associated Efficacy*

Treatment Option	Treatment Efficacy
Treatment utilizing Corticosteroids: Intravenous, oral, steroid + PE, steroid + IVIg	Not effective as first-line primary therapy
Treatment utilizing Cerebrospinal Fluid Filtration	Considered a “new” therapy; more research is needed particularly of stronger scientific merit
Treatment utilizing Immunotherapy: Plasmapheresis (plasma exchange, PE)	Effective if initiated early in the course of the illness
Treatment utilizing Immunotherapy: Intravenous Immunoglobulin (IVIg)	Equally as effective as plasmapheresis; however, is easier to administer
Treatment utilizing Plasmapheresis followed by Intravenous Immunoglobulin (PE + IVIg)	No statistically significant benefit

## **Appendix B**

### **Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy**

#### **Foundation International Letter of Support**

J. Dwayne Hooks Jr., MN, RN, FNP-BC, FACHE  
1123 Newpark View Place  
Mableton, Ga 30126

RE: Dissertation Research

Dear Mr. Hooks,

As Executive Director of the Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International, I am pleased to write this letter to demonstrate our support of your dissertation research regarding patients' recall of their experience during an acute illness with Guillain-Barre' Syndrome.

The Guillain-Barre' Syndrome Foundation International's mission is to improve quality of life for individuals and families worldwide affected by GBS, CIDP and related syndromes, and variants. Tactics that we employ that contribute to the Foundation's achievement of this mission include providing a network for individuals impacted by GBS, providing educational programs, engaging in patient advocacy, and by sponsoring research. We believe that achieving our mission will lead to us being able to ensure that every person afflicted with Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy, or GBS variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

Your research has the potential to impact quality of life for those who have suffered from GBS. Ensuring that nurses and other clinicians have information from patients that can guide their care is essential. Your research could provide nurses and other clinicians with information from the patient's perspective regarding their experience with GBS. In order to support your work, the Foundation will email GBS/CIDP Foundation International members to advise them of your important research and to ascertain their interest in participating. The email will notify them of the study and ask them to contact you directly at the contact information that you provide if they have interest in participating in your qualitative descriptive research. Potential participants will be educated that the study will include an interview and possibly a follow-up discussion to clarify any information obtained during the interview. In addition, the potential participants will be notified that their participation will remain anonymous, that any identifying information will not be disclosed, and that their participation is voluntary.

If you have any questions or need any additional information, please do not hesitate to reach out to me. I look forward to working with you further once you have received all appropriate approvals for your research proposal. I am excited about the potential impact of your research.

Sincerely,

Ken Singleton  
Executive Director  
GBS/CIDP Foundation International

## **Appendix C**

### **Participant Recruitment Notice to Guillain-Barre' Syndrome/Chronic Inflammatory**

#### **Demyelinating Polyneuropathy Foundation International Membership**

#### **Notice of Research Study**

Nursing Researchers from the University of Kansas School of Nursing are performing a research study with participants who have had a moderate to severe case of Guillain-Barre' syndrome. This research will look to better understand what the patient recalls about the period of time that they were hospitalized with moderate to severe Guillain-Barre' syndrome. What is learned from this research can be shared with nurses and other clinicians to enhance the care provided to those individuals affected by this illness.

Patients who have been diagnosed with moderate Guillain-Barre' syndrome have had paralysis of their legs (lower extremities) that affected their ability to walk (ambulate) when they were hospitalized with their illness. Patients who have been diagnosed with severe Guillain-Barre' syndrome have had paralysis of the respiratory muscles (the muscles that help in breathing) that affected their ability to breathe on their own. Patients with severe cases of Guillain-Barre' syndrome typically need help breathing with a ventilator when they were hospitalized with their illness.

You are receiving this notice because you have registered with the Guillain-Barre' Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy Foundation International and may qualify to participate in this study. Criteria to participate in this voluntary research study include: (1) adults 18 years of age and older, (2) a prior self-identified diagnosis of moderate to severe Guillain-Barre syndrome, (3) alert and oriented, (4) able to respond to interview questions, (5) English as a primary or secondary language, and (5) able to give informed consent.

If you meet participation criteria and decide to participate, you will be interviewed by a nursing researcher for approximately 60 to 90 minutes. The interview will be recorded with a digital recorder. A second telephone interview may be requested if the researcher needs to clarify any of your responses and/or to obtain any additional needed information. The primary researcher anticipates that you will not directly benefit from participating in this research study. Researchers hope that the information obtained during this research study may be useful in enhancing the care and treatment for patients who will be diagnosed with moderate to severe Guillain-Barre' syndrome in the future.

For more information, or if you have questions, regarding this research study, please contact J. Dwayne Hooks Jr., MN, RN, FNP-BC at [jhooks2@kumc.edu](mailto:jhooks2@kumc.edu) or by mobile 706-231-0840. Alternately you may contact Dr. Wanda Bonnel PhD, APRN at [wbonnel@kumc.edu](mailto:wbonnel@kumc.edu) or 913-588-3363.

## Appendix D

### Sample Snowballing Referral Letter

Dear [Mr. / Ms. Participant's LAST NAME],

Thank you for your interest and participation in Guillain-Barre Syndrome: A Qualitative Descriptive Study. I am providing you with this letter to ask you to pass along the enclosed information to individuals that you know who may also be interested in learning about, and possibly participating, in this research study. You are under no obligation to share this information and whether or not you share this information will not affect your relationship with the staff at the University of Kansas Medical Center (KUMC). Potential participants should be 18 years of age or older and thought to have had a previous diagnosis of moderate to severe Guillain-Barre' syndrome. If you or anyone you know has questions regarding this study or how to participate, researchers can be reached by email at [jhooks2@kumc.edu](mailto:jhooks2@kumc.edu) or [wbonnel@kumc.edu](mailto:wbonnel@kumc.edu) or by calling or texting the number listed below.

Thank you for your time and consideration.

Sincerely,

J. Dwayne Hooks Jr., MN, RN, FNP-BC, FACHE

Email: [jhooks2@kumc.edu](mailto:jhooks2@kumc.edu)

Mobile Number: 706-231-0840

Enclosure(s):

Research Consent Form

## Appendix E

### Additional Recruitment Strategies

Table E1

*Summary of Additional Participant Recruitment Strategies*

Strategy	Timing of strategy
Announcement of study using Appendix B Recruitment	Approximately one month
Notice to Guillain-Barre' syndrome support group leaders in Georgia (four support groups in Georgia including Atlanta, Central Georgia, Macon, and West Central Georgia chapters) and in North Carolina (four support groups in North Carolina including Charlotte, Durham, Raleigh, and Winston-Salem chapters)	after study initiated if informational redundancy not achieved

The additional recruitment strategy that will be employed in the event that informational redundancy is not achieved with the primary recruitment methods includes: announcement of the study through the nationwide network of Guillain-Barre' syndrome support groups with focus on the four support group chapters in Georgia and the four support group chapters in North Carolina. Table E1 outlines when the timing of this strategy would have been deployed if needed.



## Appendix F

### Demographic Questionnaire

#### Guillain-Barre Syndrome: A Qualitative Descriptive Study

Identifier: \_\_\_\_\_

Gender:    Male            Female

Race: \_\_\_\_\_

Marital Status at onset of GBS illness:    Single    Married/Domestic Partner    Divorced

Highest level of education: \_\_\_\_\_

Date of Birth and Current Age: \_\_\_\_\_

Age at onset of GBS illness: \_\_\_\_\_

Year GBS was diagnosed: \_\_\_\_\_

Were you told that *Campylobacter jejuni* preceded your illness:    Yes    No    Unknown

Were you told about any other illness that may have preceded your GBS:    Yes    No    Unknown

If yes, what was the illness: \_\_\_\_\_

Did you have any immunizations within the 6 months prior to your GBS:    Yes    No    Unknown

If yes, what immunization did you have and what was the approximate time prior to your diagnosis of GBS:

\_\_\_\_\_

Have you received this immunization since your diagnosis with GBS:    Yes    No

Have you received any other immunizations since your diagnosis with GBS:    Yes    No

Has anyone in your family ever been diagnosed with GBS:    Yes    No

If yes, then what was their relationship to you: \_\_\_\_\_

Were you admitted to the hospital because of your GBS diagnosis:    Yes    No

If yes, were you admitted emergently:    Yes            No

Approximately how many days did you remain in the hospital: \_\_\_\_\_

Admit Date (if known): \_\_\_\_\_ Discharge Date (if known): \_\_\_\_\_

While in the hospital, was any of your care provided in an Intensive Care Unit:    Yes    No

Were you able to walk (ambulate) during the most severe time of your illness?    Yes    No

Were your legs (lower extremities) paralyzed during the most severe time of your illness?

Yes    No

Did you need mechanical ventilatory support (ventilator or breathing machine)?    Yes    No

Were you told that your GBS was moderate or severe:        Yes    No

Did you receive care in a hospital or a specialty unit designated as a GBS Center of Excellence?

Yes    No    Unknown

How did you hear about this study:    (1) Email from GBS Foundation  
(circle the appropriate response)

(2) Ad on the GBS Website (Latest News Section)

(3) GBS FaceBook Posting

(4) From an individual who told me about the study

(5) Other: \_\_\_\_\_

## **Appendix G**

### **Interview Guide**

1. Tell me about when you were first diagnosed with Guillain-Barre syndrome (GBS).
  - P1.1 What made you go to the doctor or hospital?
  - P1.2 Tell me about your symptoms at the beginning (onset) of your illness.
  - P1.3 Tell me how you felt at the beginning (onset) of your illness.
2. Tell me what you knew about GBS before you were diagnosed with the illness?
3. Tell me about how you learned about GBS after you were diagnosed with the illness.
  - P3.1 Where did you get the information?
  - P3.2 Are there things that you know now that you would have liked to have known when you were first diagnosed with GBS?
4. Tell me about the care you got while you were in the hospital when you were diagnosed with GBS.
  - P4.1 Did you have any problems with communication? If so, how did you communicate with hospital staff (nonverbally, verbally, special communication devices)?
  - P4.2 Describe any special communication techniques or devices that were utilized during your care? Tell me how those things worked.
  - P4.3 Describe how your needs were met during the most severe time of your illness?
  - P4.4 Tell me about any needs you felt were not met during your illness.
5. Tell me about the place(s) where you got your care when you were in the hospital (Intensive Care Unit patient room, Nursing Unit patient room, etc.).
  - P5.1 Were there any care moments that were particularly good or bad?
6. Tell me about the biggest challenge(s) that you faced during the most severe time of your illness?
  - P6.1 What made this better?
  - P6.2 What made this worse?
7. What were important or key achievements (events, milestones, etc.) during your illness?

8. What did nurses (or other caregivers) do that helped you deal with your illness?

P8.1 What could nurses (or other caregivers) have done to make the care better?

9. Tell me about your emotions during this time (if participant is unsure of time will clarify by adding “the emotions that you experienced or encountered during your illness”).

P9.1 Some other people who have had GBS have told me they felt scared or anxious or depressed - did you feel any of these things? Can you tell me more about this?  
How did you deal with this (will use this only if not previously addressed by the participant)?

P9.2 What other emotions or feelings did you experience?

10. What words of wisdom would you have for another person who was just diagnosed with GBS?

11. Is there anything else that you think would be important for me to know about your experiences with GBS?

## **Appendix H**

### **Research Consent Form**

Title: Guillain-Barre Syndrome: A Qualitative Descriptive Study

Study Protocol # 00001986

You are being asked to join a research study. You are being asked to take part in this study because you have had a previous diagnosis of moderate to severe Guillain-Barre' syndrome. Patients who have been diagnosed with moderate Guillain-Barre' syndrome have had paralysis of their legs (lower extremities) that affected their ability to walk (ambulate) when they were hospitalized with their illness. Patients who have been diagnosed with severe Guillain-Barre' syndrome have had paralysis of the respiratory muscles (the muscles that help in breathing) that affected their ability to breathe on their own. Patients with severe cases of Guillain-Barre' syndrome typically need help breathing with a ventilator when they were hospitalized with their illness.

You do not have to participate in this research study. The main purpose of research is to create new knowledge for the benefit of future patients and society in general. Research studies may or may not benefit the people who participate.

Research is voluntary, and you may change your mind at any time. There will be no penalty to you if you decide not to participate, or if you start the study and decide to stop early. Either way, you can still get medical care and services at the University of Kansas Medical Center (KUMC).

This consent form explains what you have to do if you are in the study. It also describes the possible risks and benefits. Please read the form carefully and ask as many questions as you need to, before deciding about this research.

You can ask questions now or anytime during the study. The researchers will tell you if they receive any new information that might cause you to change your mind about participating.

This research study will take place at the University of Kansas Medical Center (KUMC) with Wanda Bonnel, PhD and Sandra Bergquist-Beringer, PhD as the principle investigators and J. Dwayne Hooks Jr., MN, RN, FNP-BC as the primary researcher. This research is a requirement for completion of the PhD in Nursing degree for the primary researcher. A total of about 10 to 12 people will be in the study at geographic locations across the United States.

### **BACKGROUND**

Guillain-Barre' syndrome is considered a rare disease. No research exists regarding the patients' recalled experience (memories) of care during a hospital stay caused by Guillain-Barre' syndrome. This syndrome can cause patients to rely on a ventilator (breathing machine) to assist with breathing secondary to the paralysis that is caused by this illness. This illness impacts

communication and can cause fear and anxiety in patients. Research is needed in this area to better understand what the patient experiences when they have a moderate to severe case of Guillain-Barre' syndrome.

## **PURPOSE**

By doing this study, researchers hope to learn more about the experiences that patients have during an acute illness and hospitalization with moderate to severe Guillain-Barre' syndrome. Guillain-Barre' syndrome is a disabling disorder that has multiple implications for patients. These implications include physical limitations, financial hardship, psychological effects, and impacts on support systems and family. Many of these implications, particularly during an acute illness and hospitalization, have not been fully studied. This research will look to better understand what the patient recalls about encounters during the acute illness and hospitalization with moderate to severe Guillain-Barre syndrome and what learnings can be shared with clinicians to enhance the care provided to patients affected by this illness.

## **PROCEDURES**

If you are eligible and decide to participate in this study, your participation will last approximately 90 to 120 minutes. Your participation will involve:

- The completion of a demographic questionnaire to obtain key information about you and also about your experience(s) with moderate to severe Guillain-Barre syndrome. The questions on the demographic questionnaire include, but are not limited to: age, gender, marital status, race, information about the illness, questions about events prior to your illness with Guillain-Barre' syndrome, etc. Your name will not be recorded on this form. You will select an identifier to record on the questionnaire which will be cross referenced with a participant list. Your identity will be confidential and you will choose a pseudonym that will be utilized during the interview. Only the primary researcher and the research team will know your identity.
- The completion of an interview with the primary researcher, asking open ended questions about your experience during your illness with moderate to severe Guillain-Barre syndrome. The interview will be conducted in a public space, such as a library or healthcare setting conference room meeting your need for convenience. Or if you are unable to leave your home, or are prohibited by distance from meeting face to face, you can be interviewed by phone or with online technology. The interview is expected to last 60 to 90 minutes and will be recorded with a digital recorder. The digital recording and the exact (verbatim) transcriptions of these interviews will be securely stored by the primary researcher for a period of fifteen (15) years as required by the Institutional Review Board
- After the primary researcher, and other members of the research team, have reviewed your responses to the questions from the initial interview (during the data analysis phase of the research study), a second interview may be requested to clarify any of your responses and/or to obtain any additional needed information. This second interview can

be a telephone interview and should last no more than 30 minutes.

- You also may be asked to share information about the potential for study participation with someone else you think may be interested in the study.

## **RISKS**

You may feel uncomfortable by some of the questions the researcher asks you or the questions may cause you to recall an event or events that may have been unpleasant or embarrassing during your illness with moderate to severe Guillain-Barre' syndrome. You are free at any point not to answer a question or questions and you may stop participating in the study all together.

In order to reduce the risks of disclosure if information is released, the information you provide will be treated as confidential (see Procedures section) and will not have the participants' given name on written transcripts. You are free to give only the information you choose.

There may be other risks of the study that are not yet known.

## **NEW FINDINGS STATEMENT**

You will be told about anything new that might change your decision to be in this study. You may be asked to sign a new consent form if this occurs.

## **BENEFITS**

The primary researcher anticipates that you will not directly benefit from participating in this research study. Researchers hope that the information obtained during this research study may be useful in enhancing the care and treatment provided by clinicians to patients who will be diagnosed with moderate to severe Guillain-Barre' syndrome.

## **ALTERNATIVES**

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you receive at the University of Kansas Medical Center.

## **COSTS**

There is no cost for being in the study.

## **PAYMENT TO SUBJECTS**

There is no payment for this study.

## **INSTITUTIONAL DISCLAIMER STATEMENT**

If you think you have been harmed as a result of participating in research at the University of Kansas Medical Center (KUMC), you should contact the Director, Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160. Under certain conditions, Kansas state law or the Kansas Tort Claims Act may allow for payment to persons who are injured in research at KUMC.

## **CONFIDENTIALITY AND PRIVACY AUTHORIZATION**

The researchers will protect your information, as required by law. Your health information is protected by a federal privacy law called HIPAA. By signing this consent form, you are giving permission for KUMC to use and share your health information for the purposes of this study. If you decide not to sign the form, you cannot be in the study. The researchers will only use and share information that is needed for the study. Absolute confidentiality cannot be guaranteed, but in order to minimize any risks procedures described in this document will be adhered to. The researchers may publish the results of the study. If they do, they will only discuss group results. Your name will not be used in any publication or presentation about the study.

## **QUESTIONS**

Before you sign this form, or give verbal consent, J. Dwayne Hooks Jr., MN, RN, FNP-BC ([jhooks2@kumc.edu](mailto:jhooks2@kumc.edu)), Wanda Bonnel, PhD ([wbonnel@kumc.edu](mailto:wbonnel@kumc.edu)), or Sandra Bergquist-Beringer, PhD ([sbergquist-beringer@kumc.edu](mailto:sbergquist-beringer@kumc.edu)) members of the study team should answer all your questions. You can talk to the researchers if you have any more questions, suggestions, concerns or complaints after signing this form. If you have any questions about your rights as a research subject, or if you want to talk with someone who is not involved in the study, you may call the Human Subjects Committee at (913) 588-1240. You may also write the Human Subjects Committee at Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

## **SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY**

You may stop being in the study at any time. Your decision to stop will not prevent you from getting treatment or services at KUMC. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

## **CONSENT**

Either J. Dwayne Hooks Jr., MN, RN, FNP-BC, Wanda Bonnel, PhD, or Sandra Bergquist-Beringer, PhD, member of the research team has given you information about this research study. They have explained what will be done and how long it will take. They explained any inconvenience, discomfort or risks that may be experienced during this study.



By signing this form, or providing verbal agreement, you say that you freely and voluntarily consent to participate in this research study. You have read the information and had your questions answered.

*You will be given a copy of the consent form to keep for your records.*

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Print Participant's Name

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Signature of Participant

---

Time

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Date

---

Print Name of Person Obtaining Consent

---

Signature of Person Obtaining Consent

---

Date

## Appendix I

### Participant Recruitment Notice for Social Media Sites

#### ❧ RESEARCH STUDY ❧

## GUILLAIN-BARRE' SYNDROME

Have you had a prior diagnosis of moderate to severe Guillain-Barre' syndrome?

Nursing Researchers from the University of Kansas School of Nursing are performing a research study with participants who have had a moderate to severe case of Guillain-Barre' syndrome.

This **voluntary** research study will look to better understand what the patient recalls about encounters during the acute illness and hospitalization with moderate to severe Guillain-Barre syndrome and what learnings can be shared with nurses and other clinicians to enhance the care provided to patients affected by this illness.

For more information, contact J. Dwayne Hooks Jr. at 706-231-0840 or by email at [jhooks2@kumc.edu](mailto:jhooks2@kumc.edu). You may alternately contact Wanda Bonnel, PhD, ARNP at [wbonnel@kumc.edu](mailto:wbonnel@kumc.edu) or 913-588-3363.

Guillain-Barre' Syndrome: A Qualitative Descriptive Study Protocol # 00001986

## Appendix J

Table J1

*Relationship between research questions, interview guide questions, and resulting themes*

Research Question Number	Research Question Text	Interview Guide corresponding question	Resulting Theme
1	What are patients recalled experiences of care and caregiver interactions during an episode of moderate to severe Guillain-Barre' syndrome?	4, 5.1, 6, 7, 8, 9	1, 2, 5
2	What do patients recall about characteristics and environmental conditions of the clinical area(s) where they receive care?	5, 6, 7, 9	1, 2
3	How do patients describe their change in knowledge of GBS over time from pre diagnosis to current time?	2, 3, 10	2, 3, 4, 5

## Appendix K

Table K1

Year of Diagnosis with Guillain-Barre' Syndrome

Decade	Number of participants whose GBS was diagnosed in the corresponding decade
1970 - 1979	1
1980 - 1989	2
1990 - 1999	1
2000 - 2009	4
2010 - current	6